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Abstract (Limit: 200 words)

This study **describes and analyzes a range of state-administered programs available to cover and finance the health care needed by people infected** with the human immunodeficiency virus **(HIV).** The study focuses on: Title II programs of the Ryan White CARE Act: Medicaid 2176 home and community-based waiver programs; state funded, non-Medicaid, medical assistance programs; and the actions of state health departments that address the incidence of tuberculosis, especially among people with **HIV.** The study presents assessments of administrators of Acquired Immune Deficiency AIDS service organizations at the state and local level, regarding their view of the success of these **state-**administered public programs, and the Medicare program, in addressing the health care needs of people with HIV. Data was collected on these state-administered public programs using a series of nine separate surveys that were mailed to program administrators in each state. Successful innovations developed by individual states that implement a comprehensive range of programs can serve as models, guiding other states in developing AIDS-related policies and helping to assure that all people with HIV have access to necessary health and care-related services.

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FINAL REPORT:

State-Administered Programs for HIV-Related Care
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Funded by:
Health Care Financing Administration
Department of Health and Human Services

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ABSTRACT:
STATE-ADMINISTERED PROGRAMS FOR HIV-RELATED CARE

Objectives

The objectives of this study are to describe and analyze a range of state-administered, government programs available to cover and finance the health care needed by people infected with the human immunodeficiency virus (HIV). The study focuses on: Title II programs of the Ryan White CARE Act; Medicaid 2176 home and community-based care waiver programs; state-funded, non-Medicaid, medical assistance programs; and the actions of state health departments that address the incidence of tuberculosis, especially among people with HIV illness. The research also presents assessments that administrators of AIDS service organizations at the state and local level have about how well each of these state-administered public programs (as well as the federal Medicare program) addresses the health care needs of people with HIV in their states. The project collected data on these state-administered public programs with a series of nine separate surveys that were mailed to program administrators in each state. Successful innovations developed by individual states that implement a comprehensive range of state-administered programs can serve as models to guide other states in developing AIDS-related policies that assure that all people with HIV have access to necessary health and care-related services.

EXECUTIVE SUMMARY

Objectives

The objectives of this study are to describe and analyze a range of state-administered, government programs available to cover and finance the health care needed by people who are infected with the human immunodeficiency virus (HIV). The study focuses on: Tile II programs of the Ryan White CARE Act; Medicaid 2176 home and community-based care waivers; state-funded, non-Medicaid, medical assistance programs (MAP); and the actions of state health departments that address the incidence of tuberculosis (TB), especially among people with HIV illness. The research also presents assessments that administrators of AIDS service organizations (ASOs) at the state and local level have about how well each of these state-administered public programs (as well as the federal Medicare program) addresses the health care needs of people with HIV in their states.

Survey Results

The project collected data on these state-administered public programs with a series of nine separate surveys that were mailed to program administrators in each state during 1995 through 1997. These surveys of the administrators of the various state-administered public programs identify states that have developed innovative policies to assist people with HIV gain access to needed health services. These innovative policies can then be used as models to assist other states in the development of similar AIDS-related policies for their states.

Title II Programs

The Ryan White Comprehensive AIDS Resource Emergency (CARE) Act became law in August, 1990 with the objective to improve both the quality and

availability of care for people with HIV disease and their families. Tile II of the CARE Act allows states to allocate funds among any or all of four areas: to cover home-based health services; to provide medication and other treatments; to continue private health insurance coverage; or to fund HIV care consortia.

Title II Funding Allocations. The study presents how the states are allocating Tile II funds, with most states spending the largest share of Tile II funds on HIV consortia.[a] Among the programs and services that Tile II administrators considered to be most effective at meeting the care needs of people living with HIV are: the HIV consortia; the HIV/AIDS DAPs; case management; and various home health services. The Title II administrators in most states expect the number of Title II beneficiaries to increase. If federal funding for Title II programs does not increase to keep pace with the increasing number of people expected to receive Title II benefits, then the Title II programs may not be able to provide services for all eligible people.

Consortia. The study identified a range of medical and support services that the HIV consortia funded by Title II provided during 1995 in the various states. Among the most effective consortia services identified by the study are: case management, primary medical care, drugs/medication, dental care, and home care. However, as the response from a Title II administrator in Florida summarized: "a single service cannot be identified as [most effective]. It is the continuum of care that makes Title II effective - the broad array of services covered [in Florida]." The services identified in Table 2-3 in the Final Report of this study offer examples of the broad array of medical

[a] The Title II surveys were completed before the approval by the Food and Drug Administration of the protease inhibitors. The expense of these new drugs, when used in combination therapies, may change this allocation of funding among Title II programs.

and support services that comprise the continuum of care needed by people with HIV illness to guide the HIV consortia funded by Title II.

The study also identified the medical and financial criteria necessary for individuals to become eligible for HIV consortia services. The study documents that the state Title II programs have established generous income eligibility standards for services provided by HIV consortia, especially when compared to Medicaid eligibility standards. Hence, HIV consortia funded by Title II can provide services to people infected with HIV who have incomes too high to become eligible for Medicaid coverage.

To coordinate HIV consortia programs with the state Medicaid programs, Medicaid representatives serve on Title II boards and committees in a number of states. In addition, case managers can assist individuals who have HIV disease with the Medicaid eligibility process. This role for case managers is important because a number of state AIDS program directors identified the Medicaid eligibility/application process as a barrier to the coordination of Medicaid with the Title II programs. Another barrier to Medicaid/Title II integration and coordination mentioned by AIDS program directors in a number of states is the administrative separation of the two programs in different state agencies. Coordinated meetings and cross-training programs can help overcome the integration problems created by this separate administration of the Medicaid and Tile II programs.

Generous eligibility criteria and coverage of a broad array of medical and support services by HIV consortia allow these Title II programs to strengthen the public-sector safety net for financing the care needed by people with HIV-related

illness. HIV consortia funded by Title II provide needed care to people with HIV disease before they become eligible for Medicaid or Medicare.[b]

HIV/AIDS Drug Assistance Programs. Most Title II-funded DAPs had formularies, with the number of drugs included ranging as high as 191 medications in New York during 1995. The decision to add new drugs to the DAP formulary is made by a board, panel, or committee in most states, with a number of states noting that the cost of medications or the availability of funds affects these decisions. Although it would allow health providers to prescribe the most appropriate drug therapies, the DAPs in some states do not allow the off-label use of medications.

The study also identified the medical and financial criteria necessary for individuals to become eligible for DAPs. The study documents that the state Tile II programs have established generous income eligibility standards for services provided by DAPs, especially when compared to Medicaid eligibility standards. Hence, DAPs funded by Tile II can provide drug therapies to people infected with HIV who have incomes too high to become eligible for Medicaid coverage.

DAPs funded by Tile II in a number of states cover the prescription drug needs of Medicaid recipients with HIV or AIDS in excess of the Medicaid limits implemented in these states. However, the DAP in South Carolina responded that due to the lack of funds it can no longer cover the drugs needed by Medicaid recipients with HIV or

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[b] For a person with HIV illness to become eligible for Medicare requires meeting eligibility criteria for Social Security Disability Insurance (SSDI), including disability status, sufficient work-related history, and a 29-month waiting period (5 months from disability status for SSDI payment to begin, then 24 additional months for Medicare coverage to begin). (See Baily, M., Biiheimer, L., Woolridge, J., Langwell, K., and Greenberg, W. "Economic Consequences for Medicaid of Human Immunodeficiency Virus Infection." Health Care Financing Review (1990 Annual Supplement): 97-108.

AIDS that exceed the drug utilization limits implemented by the Medicaid programs in that state. DAPs also can provide drug coverage to people with AIDS or HIV who are in the process of becoming eligible for Medicaid benefits.

DAPs in a number of states reported the use of waiting lists. Given the encouraging results of the new protease inhibitors in treating HIV infection, and the $12,000 to $15,000 annual cost of these and other drugs per person when used in a combination therapy or a "three-drug cocktail", the DAPs funded by Tile II will face increasing fiscal pressures (Altman, 1996; Winslow, 1996). In fact, some states are already tightening eligibility, reducing the number of covered drugs, or implementing copayments (McGinley, 1996). If federal funding for Tile II programs in the future does not keep pace with the expected increase in the number of people eligible for Tile II services, and the costs of services provided, then the public-sector safety net for financing HIV-related care will be weakened.

Home and Community-Based Care. The study identified a range of home and community-based care services funded by Tile II in various states during 1995. Among the most effective services identified by the study are: case management, personal/attendant care, homemaker/chore services, home I.V. therapy, and transportation.

Coordination of the Title II programs with the Medicaid Home and Community-Based Care Waiver programs will increase the range of services available to people with AIDS and HIV infection while conserving limited Title II resources. Contracting with Medicaid-certified providers of home and community-based services will allow the Title II, programs to promote the continuity of care as patients become eligible for Medicaid, as well as help assure that Title II is the payer of last resort.

Health Insurance Continuation Programs. In all states implementing the health insurance continuation program with Tile II funds, the programs cover health insurance premiums, with a few states also covering copayments, coinsurance, and/or deductibles. The study documents that the state Title II programs have established generous income eligibility standards for assistance provided by the health insurance continuation programs. Hence, the health insurance continuation programs funded by Tile II can provide coverage to people infected with HIV who have incomes too high to become eligible for Medicaid coverage.

Title II **Summary.** Generous eligibility criteria and coverage of a broad array of health services by the programs funded by Title II of the CARE Act strengthens the public-sector safety net for financing the care needed by people with HIV-related illness. Title II programs provide needed care to people with HIV disease before they become eligible for Medicaid or Medicare. Generous eligibility criteria (or no income restrictions in some states), however, can become a double-edged sword. If federal funding for Tile II programs is not sufficiently increased to keep up with the increasing number of people expected to receive benefits from Title II programs, or if future federal Medicaid reform allows the states to establish even more restrictive Medicaid eligibility standards, then the Tile II programs may not be able to provide services for all eligible people. This could result in the use of waiting lists, reduced services, some other forms of rationing, or the implementation of more restrictive eligibility criteria. For example, the DAPs funded by Title II of the CARE Act in a number of states have implemented waiting lists for people to receive medications because funding is not adequate to meet the need for this coverage. If federal funding for Tile II programs in the future does not keep pace with the expected increase in the number of people

eligible for Tile II services, then the public-sector safety net for financing HIV-related care will be weakened.

Medicaid Home and Community-Based Care Waivers

The Medicaid Home and Community-Based Care Waiver programs allow the states considerable flexibility in defining the groups of people to be served and the range of services to provide. These waivers allow the states to implement innovative programs to provide community-based, long-term care to people with AIDS. Given their disability status, people with AIDS who meet the more generous eligibility standards established for these waiver programs may receive services from the Medicaid Home and **Community-Based** Care waiver programs for the Elderly and Disabled or from a separate waiver for the Disabled (Buchanan, **1996).**[c] In addition, 15 states and the District of Columbia (implemented in December, 1996) have established AIDS-specific Medicaid Home and Community-Based Care waiver programs and Maine expects to implement this AIDS-specific waiver during 1997.

Case management services are advocated as critical to the care of people with AIDS, with the role of the case manager extending beyond the coordination of health services to include helping people with AIDS cope with their social and emotional needs. As Tables 6-1, 6-3, and 6-5 in the Final Report for this project demonstrate, the Medicaid Home and Community-Based Care waiver programs for people with AIDS, the Elderly and Disabled, and for the Disabled offer case management services in most states. Case management was identified by Medicaid administrators in the survey conducted for this research as among the most effective waiver services

[c] These waiver programs for the disabled, however, are limited in many states to the developmentally disabled.

provided to people with AIDS. Other services provided by these waiver programs that the Medicaid administrators identified as most effective at meeting the care needs of people with AIDS are: personal care, homemaker services, assistive technologies, emergency response, medical social services, in-home and inpatient respite care, counseling, home intravenous therapy, nutritional counseling and supplements, attendant care, hospice care, home-delivered meals, and unlimited prescription drug coverage. (See Tables 6-2, 6-4, and 6-6 in the Final Report.) State Medicaid programs not administering the AIDS-specific waiver program can include these services in their waiver programs for the elderly and disabled. Since people with AIDS are typically eligible for these waiver programs due to their disability status, even states without the AIDS-specific waiver can then offer Medicaid recipients with AIDS a broad range of needed home care and community-based services.

State-Funded Medical Assistance Programs

A number of states implement state-funded MAPs to provide health care to low-income people. However, a review of the literature revealed no published papers that describe these programs. A two-step survey process was used to identify states that implemented state-funded MAPs during 1997 and to collect data describing, eligibility, coverage, and payment policies for these programs.

Typically, requirements for MAP eligibility are restrictive but the range of health services covered tends to be comprehensive in most states. MAP payment levels for the health services included in the study typically are less than the Medicaid payment level, which may make it difficult for MAP beneficiaries to gain access to these services. In spite of these eligibility and payment level restrictions, these state-funded MAPs can provide health coverage to people with HIV disease who lack other health

insurance. As Table 7-2 in the Final Report illustrates, most of these state-funded MAPs cover a comprehensive range of health services needed by people infected with HIV, including acute care services and prescription drugs, as well as necessary home and community-based care and support services.

AIDS **Service Organizations**

Public programs are the primary payers for the health and care-related services provided to people with HIV. The coverage, payment, and utilization policies implemented by these public programs affect the care that people with HIV **receive.** ASOs were surveyed to identify effective services covered, and effective services that are not covered, by these public payers of HIV-related care, as well as to identify problems that people with HIV illness have with these programs.

As Table 8-l in the Final Report illustrates, the state Medicaid programs cover a range of health services that meet the needs of people with HIV, with prescription drug coverage mentioned most frequently by the ASOs. However, a number of states place restrictive utilization limits on these health services (for example, three prescriptions per month), often below the levels needed by people with HIV illness. Table 8-1 in the Final Report also presents effective health and care-related services that the state Medicaid programs do not cover. All of these services can be provided with the Medicaid home and community-based care waiver programs for people with AIDS/HIV and for the elderly and disabled (people with AIDS can access this programs due to their disability status). Expanded use of these waiver programs would allow the state Medicaid programs to target effective health and care-related services to people with HIV illness. In addition, due to more generous income eligibility standards, it is easier

for people with HIV to qualify for these waiver services than for traditional Medicaid coverage (Buchanan, 1996).

Table 8-2 in the Final Report presents effective health and care-related services provided to people with HIV that are funded by Title II of the Ryan White CARE Act. In addition to prescription drugs and physician services, the Tile II programs offer support-related services such as food and nutrition, transportation, alternative therapies, mental health and support groups, adult and child day care, and legal services. Limited funding for Title II programs was the problem most frequently identified by the ASOs. A number of ASOs also mentioned a lack of awareness of Title II programs as a problem for people with HIV illness.

As Table 8-3 in the Final Report summarizes, the ASOs identified a blend of both health care and social services funded by Tile I of the Ryan White CARE Act as most effective at meeting the needs of people with HIV illness. One AS0 responded that the Title I program in its service area does not cover support services for family and friends of people with HIV disease, with these people feeling "left out." Another AS0 reported the lack of transportation to care results in the loss of care.

As Table 8-4 in the Final Report presents, the Medicare program covers a range of health services necessary for the treatment of acute illness, except for prescription drugs. Given the success of the combination drug therapies in combatting the progression of HIV disease, the ASOs identified the lack of Medicare coverage of prescription drugs as a major problem for people with HIV illness. One AS0 responded that if Medicare was "the only health insurance a disabled person has, lack of access to medications is a significant problem." Another AS0 noted that given the focus of Medicare coverage on acute care/medical care, the lack of Medicare

coverage of support services is a problem for people with HIV disease. The length of time for Medicare eligibility (29 months) is a severe problem for people with HIV illness. Medicare cost sharing responsibilities can be more than most people with AIDS can afford.

One AS0 responded that the Title II programs need to address the concerns of people who may recover from HIV-related disability with job and re-education programs. Given the success of the combination drug therapies in combatting the progression of HIV disease, all public programs covering HIV-related care, not just the CARE Act programs, will need to address the. health and care-related needs of people who recover from HIV-related disability. If people recover from HIV-related disability, will they lose their disability status? This disability status, for example, is a key element of eligibility for Medicaid coverage. Without this coverage, will they still have access to the combination drug therapies and other health and care-related services that led to their recovery? The eligibility of people who recover from HIV-related disability for public programs will become an increasingly important issue in the near future as new developments in drug therapies and other treatments combat the progression of HIV disease.

Tuberculosis Control Policies

Incentives and Enablers for Compliance with TB Drug Regimens. The results of the survey conducted for this study indicate that public health departments in almost all states are implementing the incentives and enablers that TB experts advocate to encourage patients to comply with drug regimens in efforts to control this disease. The implementation of these TB incentives, along with public health screening and treatment programs combined with dramatically increased federal

funding for TB control during federal fiscal year 1993, may help to explain why the incidence of TB resumed its long term decline in the United States in 1993 after a decade of resurgence.

Public Programs to Fund Treatment Services. Aggravating and enhancing the threat of TB in the United States has been the emergence of AIDS. The spread of TB among people with AIDS has important public health consequences because TB may be the only AIDS-related disease that can be transmitted to people who are not infected with HIV (Hopewell, 1992). With the increasing incidence of AIDS in the United States, public health programs must be maintained and expanded to control TB to protect the public health and the health of people with AIDS.

Based on the results observed in New York Cii and other areas, DOT programs have been successful in the control and treatment of TB. Similarly, nursing case management offers a comprehensive approach to TB treatment, assigning outreach workers, initiating DOT, and assisting the TB patient with any necessary services to ensure compliance with therapy. According to the responses to the survey conducted for this study, public health departments in all states reported the use of DOT programs and most states utilized nursing case management.

The increased use of nursing case management, TB outreach workers, and DOT programs to treat and control TB may require increased public health expenditures during the short term in a political environment of contracting public resources. However, each dollar spent on TB control programs produces savings of three to four dollars in averted TB treatment costs, with even greater savings produced by controlling multi-drug resistant TB Institute of Medicine, 1992). Hence, nursing

case management, DOT, outreach workers and other TB control efforts are highly cost/effective (Frieden, et al., 1995).

Evaluating TB patients for eligibility for Medicaid, Medicare, and the Ryan White programs can provide resources to care for people with TB. The home and community-based care programs funded by Medicaid and by Title II of the CARE Act can be especially helpful to public health departments in the fight against TB, covering case managers, outreach workers, and the health professionals for DOT programs provided to eligible people with TB.

The results of the survey conducted for this study indicate that public health departments in almost all states are implementing the programs and policies that TB experts advocate to control this disease. The resurgence of TB in the United States during the 1980s, however, illustrates that the danger of TB to the nation's health is a constant threat. Utilizing Medicaid, Medicare, and the programs funded by the Ryan White CARE Act can provide additional resources to fund case management, directly observed therapy, outreach programs, and other services that are effective at combatting TB among people with HIV infection.

Policy Implications

This study creates a state-by-state archive of state-administered health programs available to people with HIV. These data help identify any holes in the public-sector safety net of health coverage for people with HIV-related conditions and identify other state-administered programs that help close these gaps in coverage. Successful innovations developed by individual states that develop a comprehensive range of state-administered programs can serve as models to guide other states in

developing AIDS-related policies that assure all people with HIV have access to necessary social and health services.

Conclusions

Given the success of the combination drug therapies in combatting the progression of HIV disease, all public programs covering HIV-related care will need to address the health and care-related needs of people who recover from HIV-related disability. If people recover from HIV-related disability, will they lose their disability status? This disability status, for example, is a key element of eligibility for Medicaid coverage. Without this coverage, will they still have access to the combination drug therapies and other health and care-related services that led to their recovery? The eligibility of people who recover from HIV-related disability for public programs will become an increasingly important issue in the near future as new developments in drug therapies and other treatments combat the progression of HIV disease. The recovery from HIV-related disability and adequate funding for public programs to provide health coverage to people with HIV are among the most important HIV-related issues in future public policy debates.

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Chapter 1
The Ryan White CARE Act: The Allocation of Title II Funding Among Programs by the States[a]

Introduction

The Ryan White Comprehensive AIDS Resource Emergency (CARE) Act became law in August, 1990 with the objective to improve both the quality and availability of care for people with HIV disease and their families.' This legislation authorized: grants to metropolitan areas with the largest number of AIDS cases to help provide emergency services (Title I); grants to the states to improve the quality, availability, and organization of health and related support services (Title II); grants to state health departments for AIDS early intervention services (Title Ill-a) and community-based primary care facilities (Title III-b); and grants for research and evaluation initiatives (Title IV).[2] Title II allows states to allocate funds among any or all of four areas: to cover home-based health services; to provide medication and other treatments; to continue private health insurance coverage; or to fund HIV care consortia.[3] The objective of this paper is to identify how the states are allocating Title II funds among these four areas, as well as for planning, evaluation, and administration. (The states may use up to 10 percent of Title II funds for planning, evaluation, and administration.)[4] In addition, the paper presents the number of people receiving Title II benefits in each state, as well as the assessments of which Title II services or programs are the most effective at meeting the care needs of people with HIV.

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[a]This research is published in AIDS & PUBLIC POLICY JOURNAL, Vol. 12, No. 3, 1997.

Methodology

To identify how the states are allocating Title II funds, the state AIDS program directors were surveyed. The names and addresses of these directors in each state were obtained from the National Alliance of State and Territorial AIDS Directors' and the federal Health Resources and Services Administration.' A questionnaire was mailed to the AIDS program directors in May, 1995, with three additional mailings sent to states not responding. When the survey was completed in early 1996, AIDS program directors (or their staffs) in 49 states and the District of Columbia provided data (no reply was received from Rhode Island). The survey responses were summarized into tables and mailed to the survey participants for verification and updates in April, 1996.

Funding Allocation

The questionnaire asked the AIDS program directors to indicate how Tile II funds were allocated among HIV consortia, HIV/AIDS drug assistance programs (DAP), home and community-based care, continuity of private health insurance coverage, and planning, evaluation, and administration in their state during 1995, 1994, and 1993. The responses are summarized in Table l-l. In most states the majority of Title II funds were allocated to HIV consortia. In many states the funding trend has been a declining percentage of funds allocated to HIV/AIDS DAP and an increasing percentage of funds allocated to HIV consortia. In a number of states the AIDS program directors reported that while funds may not have been directly allocated to a particular program area, HIV consortia provided these services. In Texas, for example, home and community-based care services and the continuation of private health insurance are among the services provided by HIV consortia. In addition, in

Table I-I
Programs Funded by Title II of the Ryan White CARE Act during 1995:
Allocation of Funding

	Percentage Allocation of Title II Funds														
	HIV Consortia			AIDS/HIV Drugs			Home and Community-Based Care Services			Continuity of Private Health Insurance			Planning, Evaluation and Administration		
	1995	1994	1993	1995	1994	1993	1995	1994	1993	1995	1994	1993	1995	1994	1993
Alabama	50%	22.5%	17%	50%	54.7%	74.7%	not applic.	16.5%	not applic.	not applic.	not applic.	not applic.	not applic.	6.3%	8.2%
Alaska	100%	99%	99%	Part of Consortium activities			Part of Consortium activities			Part of Consortium activities			0%	1%	1%
Arizona	76.5%	75.4%	46%	18%	17.9%	21%	50.5%	0%	0%	0%	0%	0%	0%	5.6%	3.6%	2.6%
Arkansas	97%	90%	91%	60%	60%	60%	no answer	no answer	no answer	no answer	no answer	no answe	10%	10%	10%
California	50%	50%	50%	30.3%	30%	29.5%	4.7%	4.7%	7.0%	5.0%	5.3%	3.5%	10%	10%	10%
Colorado	84.5%	84.8%	47%	3.1%	3.4%	37%	induded in consortium		6%	2.4%	1.8%	0%	19%	10%	10%
Connecticut	67%	65%	55%	23%	25%	35%	0%	0%	0%	0%	0%	0%	10%	10%	10%
Delaware	50%	45%	21%	25% (includes treatments)	29%	35%	13%	10%	18%	10%	15%	24%	4%	2%	3%
District of Columbia	55%	59%	54%	21%	22%	21%	14%	9%	15%	not applicable			10%	10%	10%
Florida	51%	53%	50%	31%	34%	37%	not applicable			12%	7%	4%	6%	6%	9%
Georgia	55%	57%	50%	21%	22%	32%	1%	1%	1%	16%	14%	13%	7%	6%	4%
Hawaii	45%	45%	45%	24%	24%	24%	0%	0%	0%	21%	21%	21%	10%	10%	10%
Idaho	46.8%	46.8%	0%	48.2%	48.2%	95%	not applicable			not applicable			data not available		
Illinois	72%	70%	50%	11%	10%	31%	0%	0%	0%	11%	13%	10%	1%	2%	4%
Indiana	53%	36%.		*	42%**	58%	*	0%	0%	0%	0%	*	5%	6%	*
	* data not available; ** We have carryover from our first year that we will be adding to this [drug assistance] program. The actual amount will increase.														
Iowa	90%	90%	90%	induded in program		inconsortia decentralized	0%	0%	0%	0%	0%	0%	10%	19%	10%
Kansas	36%	38%	0%	44%	42%	72%	7%	7%	9%	3%	3%	9%	10%	10%	10%
Kentucky	0%	0%	0%	38.9%	39.3%	32.4%	37.5%	41.1%	43.4%	21.3%	18.9%	20.0%	2.3%	0.7%	4.2%
Louisiana	75%	75%	75%	0%	9%	0%	15%	15%	15%	10%	10%	10%	5%	5%	5%
Maine	0%	0%	0%	40%	0%	35%	52%	42%	40%	0%	0%	0%	10%	0%	0%
Maryland	68%	65%	71%	13%	14%	7%	9%	11%	12%	0%	0%	0%	10%	10%	10%
Massachusetts	75%	75%	75%	10%	10%	10%	10%	10%	10%	0%	0%	0%	5%	5%	5%
Michigan	80%	78%	75%	10%	10%	10%	2%	5%	8%	0%	0%	0%	5%	6%	4%
	(During 1995 an estimated 2% of total spending was allocated to women, children and families.)														
Minnesota	not applicable			11%	15%	46%	70%	54%	41%	9%	21%	13%	10%	10%	10%
Mississippi	0%	0%	0%	86%	66%	66%	33%	33%	33%	0%	0%	0%	0%.	0%	0%
Missouri	50%	50%	50%	24%	22%	42%	0%	0%	0%	0%	0%	0%	10%	10%	10%
Montana	51.0%	52.8%	not avail.	42.0%	40.0%	not avail.	0%	0%	not avail.	7.0%	7.2%	not avail.	0%	0%	not avail
Nebraska	56%	42%	20%	34%	42%	67%	0%	0%	3%	0%	6%	N.A.	10%	10%	10%

Table I-I
Programs Funded by Tiie II of the Ryan White CARE Act during 1995:
Allocation of Funding

	Percentage Allocation of Title II Funds														
	HIV Consortia			AIDS/HIV Drugs			Home and Community-Based Care Services			Continuity of Private Health Insurance			Planning, Evaluation and Administration		
	1995	1994	1993	1995	1994	1993	1995	1994	1993	1995	1994	1993	1995	1994	1993
Nevada	28%	16%	5%	32%	35%	50%	30%	39%	35%	0%	0%	0%	10%	10%	10%
New Hampshire	data not available														
New Jersey	50%	50%	50%	28%	27%	31%	9%	12%	10%	3%	2%	0%	10%	10%	10%
New Mexico	(Verified data not available)														
New York	58%	54%	50%	33%	36%	40%	0%	0%	0%	0%	0%	0%	9%	10%	10%
	("Home and Community-based services are provided through consortia."														
North Carolina	90%	90%	90%	0%	0%	0%	0%	0%	0%	0%	0%	0%	10%	10%	10%
North Dakota	35%	35%	35%	55%	55%	55%	0%	0%	0%	0%	0%	0%	10%	10%	10%
Ohio	60%	60%	60%	30%	30%	30%	2%	2%	0%	0%	0%	0%	4%	4%	0%
Oklahoma	32%	23%	22%	46%	48%	71%	16%	20%	0%	0%	0%	0%	7%	8%	7%
Oregon	77%	66%	47%	14%	25%	43%	0%	0%	0%	0%	0%	0%	9%	9%	10%
Pennsylvania	95%	77%	50%	0%	18%	45%	0%	0%	0%	0%	0%	0%	5%	5%	5%
Rhode Island	no response to the survey														
South Carolina	79%	79%	54%	12%	16%	38%	0%	0%	0%	0%	0%	0%	9%	4%	8%
South Dakota	0%	0%	0%	70%	70%	70%	15%	15%	15%	5%	5%	5%	10%	10%	10%
Tennessee	78%	62%	0%	5%	6%	96%	8%	25%	0%	0%	0%	0%	9%	7%	4%
	("In March, 1995 a new administration took over Ryan White [in Tennessee] and much revamping is in process.")														
Texas	75%	75%	82%	17%	17%	11%	included in HIV consortium			included in HIV consortium			8%	8%	7%
Utah	60%	63%	no answer	25%	24%	no answer	10%	8%	no answer	0%***	0%	0%	5%	5% (admin.)	0%
										***unless funding is increased					
Vermont	32%	30%	30%	65%	60%	67%	0%	0%	0%	0%	0%	0%	2%	10%	3%
Virginia	60%	61%	64%	24%	24%	27%	0%	0%	0%	6%	5%	0%	10%	10%	9%
Washington	71%	71%	69%	9%	14%	20%	10%	5%	1%	0%	0%	0%	10%	10%	10%
West Virginia	67%	55%	64%	30%	40%	33%	0%	0%	0%	0%	0%	0%	3%	5%	3%
Wisconsin	86%	85%	90%	2.5%~	2.5%~	0%~	0%	0%	0%	2.5%~	2.5%~	0%~	10%	10%	10%
	~"State funds purchase medications and pay [health insurance] premiums; Ryan White funds cover program [administrative] costs."														
Wyoming	0%	0%	0%	80%	80%	80%	5%	5%	5%	8%	8%	8%	7%	7%	7%

NOTE: See the note at the end of this chapter for references to other research providing detailed presentations of the implementation of each of these four programs funded by Title II of the Ryan White CARE Act in each state.

Source: Robert J. Buchanan, Ph.D., Department of Community Health, University of Illinois, a 1995 survey of state program administrators, Title II of the Ryan White CARE Act. This research was funded by a grant from the Health Care Financing Administration, U.S. Department of Health and Human Services (grant # 18-P-90286/5-01).

Wisconsin state funds purchase medications and pay premiums for the continuation of private health insurance.

The **Number of Tiile II Beneficiaries**

The questionnaire asked the AIDS program directors to "provide the number of people with HIV who received benefits from all Tile II programs in your state during 1994." These data are reported in Table l-2. The questionnaire also asked the AIDS program directors to estimate how the number of people receiving **Title** II benefits in their state during 1995 compared to 1994 and to compare the number of **Title II** beneficiaries in 1994 to the number in 1993. As Table 1-2 illustrates, the AIDS program directors in most states responded that the number of Tile II beneficiaries increased in 1995 and 1994 when compared to the previous year.

Effective Title II Services

The questionnaire asked the AIDS program directors to list the **Title** II services and programs most effective at meeting the care needs of people with HIV in their state during 1995. Their responses are summarized in Table l-2. Among the most frequently mentioned services or programs are: the HIV consortia; the HIV/AIDS **DAPs;** case management services; and various home health services. However, as Table l-2 illustrates, the survey identified a wide range of services and programs that the AIDS program directors considered most effective at meeting the care needs of people living with HIV. As the response from Virginia indicates: "This [listing of the most effective **Title** II services and programs] is difficult to say because [rile **II]** is considered such a successful program."

Table I-2
Programs Funded by Tii II of the Ryan Whii CARE Act during 1995:
The Number of People Receiving Tii II Benefits and Medicaid Coordination with Title II

	The Number of People Receiving Title II Benefits:			The Most Effective Title II Services and Programs Meeting the Care Needs of People with HIV During 1995:
	1994	1995 Compared to 1994	1994 Compared to 1993	
Alabama	2,000	increase in 1995	increase in 1994	drug reimbursement and consortia
Alaska	370	remain the same	increase in 1994	case management through consortia lead agencies
Arizona	1,500	increase in 1995	increase in 1994	primary medical care, dental services, case management, and the drug assistance program (DAP)
Arkansas	1,068	increase in 1995	increase in 1994	primary care, drugs, case management, and lab monitoring
California	40,330	increase in 1995	increase in 1994	"All programs effective at meeting needs of specific target populations."
Colorado	4,800	increase in 1995	increase in 1994	"Case management services, primary health and dental care. AIDS Drug Assistance program and insurance continuation program are very effective."
Connecticut	1,150 (unduplicated)	increase in 1995	increase in 1994	case mgt. services, transportation assistance, client special care fund, primary care services
Delaware	1,000	increase in 1995	increase in 1994	drug reimbursement and consortium
District of Columbia	2,158	increase in 1995	increase in 1994	D.C. Consortium: case mgt; AIDS Drug Assistance Program; Home & Community Based Care Program
Florida	19,705	increase in 1995	increase in 1994	no answer to the question
Georgia	5,265	increase in 1995	increase in 1994	statewide consortia
Hawaii	830	decrease in 1995	increase in 1994	"All programs effective at meeting needs of specific target populations."
Idaho	80	increase in 1995	increase in 1994	no answer to this question
Illinois	5,600	increase in 1995	increase in 1994	no answer to this question
Indiana	no answer	increase in 1995	increase in 1994	drug assistance program, early intervention services, and care coordination
Iowa	700	increase in 1995	increase in 1994	case mgt., drug assistance, assistance with housing, and emergency assistance
Kansas	175	increase in 1995	increase in 1994	Case mgt. "really helps to bring people to needed services."
Kentucky	1,329	increase in 1995	increase in 1994	Home & Community Based Care program (transportation, respite care, dental, and primary care) and the drug assistance program purchasing 16 HIV-related medications
Louisiana	3,500	no answer	no answer	all services
Maine	750+	increase in 1995	increase in 1994	case mgt services funded with Title II and state funds
Maryland	9,465	increase in 1995	increase in 1994	"We believe that each Title II-funded service is effective."
Massachusetts	5,000	increase in 1995	increase in 1994	drug reimbursement, consortia client services, and home and community-based care
Michigan	5,500 not undu-plicated	During these time periods "we could not unduplicate clients across providers."		case management and drug assistance
Minnesota	1,138	increase in 1995	increase in 1994	insurance continuation; drug program, case management, and dental program
Mississippi	336	increase in 1995	increase in 1994	drug assistance program and home-based program
Missouri	1,471	increase in 1995	increase in 1994	medication, home health, and service coordination are the most frequently utilized.
Montana	110	remain the same	decrease in 1994	consortium care and drug reimbursement program
Nebraska	400	increase in 1995	increase in 1994	consortia client services and drug assistance program

Table I-2
Programs Funded by Title II of the Ryan White CARE Act during 1995:
The Number of People Receiving Title II Benefits and Medicaid Coordination with Title II

	The Number of People Receiving Title II Benefits:			The Most Effective Title II Services and Programs Meeting the Care Needs of People with HIV During 1995:
	1994	1995 Compared to 1994	1994 Compared to 1993	
Nevada	2,750	increase in 1995	increase in 1994	consortium services for people without care and drug assistance program "has been expanded and has been a tremendous success for clients."
New Hampshire	data not available			
New Jersey	14,105	increase in 1995	increase in 1994	AIDS Drug Programs, HIV Home Care Program, HIV Health Insurance Continuation Program
New Mexico	600+	increase in 1995	increase in 1994	no answer to the question
New York	160,000*	increase in 1995	increase in 1994	primary care, therapeutic drugs, home care, case management, nutrition/foods, transportation, counseling, and support
	*Unduplicated count; includes approximately 100,000 people reached through informational and outreach services."			
North Carolina	about 3,000	increase in 1995	increase in 1994	case management, in-home care, and transportation
North Dakota	12	increase in 1995	increase in 1994	drug reimbursement
Ohio	3,120	increase in 1995	increase in 1994	drug assistance program and home health
Oklahoma	652	increase in 1995	increase in 1994	HIV Home Health Program (Home and Community Care) and case management (HIV Consortium)
Oregon	3,000	increase in 1995	increase in 1994	medical care, case mgt., counseling; client advocacy, and drug assistance program
Pennsylvania	not available	increase in 1995	increase in 1994	Many programs appear responsive to the health care needs of people with AIDS and HIV. "Evaluation has not indicated that one model works best, in part due to differences between rural and urban systems of health care."
Rhode Island	no response to the survey			
South Carolina	3,000	increase in 1995	increase in 1994	"HIV consortia in South Carolina are doing a terrific job and the drug assistance program is too."
South Dakota	34	increase in 1995	remain the same	providing drugs
Tennessee	over 200	increase in 1995	decrease in 1994	**
	**During 1993 100% of Title II funding went to the drug assistance program. In 1994 Medicaid was dropped and a managed care program [TennCare] was implemented. "Thus between 1994 and 1995 we totally revamped our entire Title II program. Not everything is fully up and running yet except case managers. So it is hard to give a good overview. TennCare covers all Medicaid recipients plus uninsurables and working poor. Much goes for case managers, dental, and other support services."			
Texas	9,183	increase in 1995	increase in 1994	health insurance continuation program
Utah	670 (unduplicated)	increase in 1995	increase in 1994	"Drug therapy, then other essentials such as dental, labwork."
Vermont	55	increase in 1995	increase in 1994	drug assistance fund
Virginia	2,600	increase in 1995	increase in 1994	"This is difficult to say because this is considered such a successful program."
Washington	1,800	remain the same	increase in 1994	"Consortia and prescription treatments."
West Virginia	380	increase in 1995	increase in 1994	Consortia
Wisconsin	850	increase in 1995	increase in 1994	case management and transportation
Wyoming	60	increase in 1995	increase in 1994	drugs, primary care, and lab tests

NOTE: See the note at the end of this chapter for references to other research providing detailed presentations of the implementation of each of these four programs funded by Title II of the Ryan White CARE Act in each state.

Source: Robert J. Buchanan, Ph.D., Department of Community Health, University of Illinois, a 1995 survey of state program administrators, Title II of the Ryan White CARE Act. This research was funded by a grant from the Health Care Financing Administration, U.S. Department of Health and Human Services (grant # 18-P-90286/5-01).

Summary and Discussion

The study presents how the states are allocating Title II funds, with most states spending the largest share of Tile II funds on HIV consortia. Among the programs and services considered to be most effective at meeting the care needs of people living with HIV are: the HIV consortia; the HIV/AIDS DAPs; case management; and various home health services. The AIDS program directors in most states expect the number of Title II beneficiaries to increase. If federal funding for Title II programs does not increase to keep pace with the increasing number of people expected to receive Tiile II benefits, then the Tiile II programs may not be able to provide services for all eligible people. This could result in the use of waiting lists, reduced services, some other forms of rationing, or the implementation of more restrictive eligibility criteria. Inadequate federal funding of CARE Act programs will weaken the public-sector safety net for financing HIV-related care.

NOTE: Detailed discussions of each of the four programs funded by Title II of the Ryan White CARE Act in each state have been published in AIDS & PUBLIC POLICY JOURNAL: Buchanan, "Consortia Programs Funded by Tile II of the Ryan White CARE Act," AIDS & PUBLIC POLICY JOURNAL 11(3), 1998; Buchanan and Smith, "Drug Assistance Programs Funded by Tile II of the Ryan Whiie CARE Act," AIDS & PUBLIC POLICY JOURNAL 11(4), 1998; Buchanan, "Home and Community-Based Care Programs Funded by Tile II of the Ryan White CARE Act," AIDS & PUBLIC POLICY JOURNAL 12(1), 1997; and Buchanan, "Health Insurance Continuation Programs Funded by Title II of the Ryan White CARE Act," AIDS & PUBLIC POLICY JOURNAL 12(2), 1997.

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Chapter 2
Consortia Services Funded by Title II of the Ryan White CARE Act[a]

Introduction

The Ryan White Comprehensive AIDS Resource Emergency (CARE) Act (Public Law 101-381) was enacted in August, 1990 to improve both the quality and availability of care for people with HIV disease and their families.' The original legislation authorized: grants to metropolitan areas with the largest number of AIDS cases to help provide emergency services (Title I); grants to the states to improve the quality, availability, and organization of health and related support services (Title II); grants to state health departments for AIDS early intervention services (Title Ill-a) and community-based primary care facilities (Title ill-b); and grants for research and evaluation initiatives, including demonstration programs for pediatric AIDS research (Title IV).[2] Title II of the CARE Act allows states to allocate funds among any or all of four areas to cover home-based health services, to provide medication and other treatments, to continue private health insurance coverage, or to fund HIV care consortia.[3]

Although the Ryan White legislation did not established income eligibility restrictions for people to receive CARE act services, the law did specify that CARE Act programs must be the payer of last resort.[4] However, Ryan White funds can be used to pay for care provided to Medicaid recipients if the state Medicaid program does not cover a needed health service or if a Medicaid recipient's need for a health service exceeds the Medicaid program's limits on utilization. If a state Medicaid program does

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not cover hospice care, for example, a Medicaid recipient can receive that service through a program funded by the CARE Act, if available. Similarly, if a Medicaid recipient needs more home nursing visits then allowed by the state Medicaid program, programs funded by the CARE Act may pay for additional home nursing care.[5]

HIV care consortia are responsible for planning and coordinating a comprehensive continuum of outpatient health and related support services.[6] The CARE Act specifies five functions for consortia: assess the service needs of all populations with HIV disease; develop a comprehensive continuum of outpatient health and related support services to meet the identified needs; promote the coordination and integration of community resources; use case management to assure continuity of services; and evaluate the consortia's effectiveness at meeting service needs and providing cost-effective alternatives to inpatient hospital care.' The objective of this paper is to identify how the states are using Title II funds to provide consortia services. The paper discusses characteristics of the consortia established by the states, the health services and related support services provided by the consortia, medical and financial eligibility criteria, and coordination with the state Medicaid program.

Methodology

To identify how the states are using Title II funds to implement consortia programs, state AIDS program directors were surveyed. The names and addresses of these directors in each state were obtained from the National Alliance of State and Territorial AIDS Directors.' In addition, the address file was updated with the names and addresses of AIDS program directors obtained from the Health Resources and Services Administration of the federal government.[9]

Survey Process

A consortia questionnaire was mailed to these AIDS program directors in May, 1995. Three additional mailings of the questionnaires were sent to the states not participating in the survey. When the survey was completed in early 1996, AIDS program directors (or their staffs) in 48 states and the District of Columbia provided consortia data (no replies were received from New Hampshire and Rhode Island). The survey responses were summarized into tables and mailed to the AIDS program directors for veriication and updates in April, 1996. Updates and any additional information received during the veriication process were added to the final tables used in this paper.

Incidence of AIDS

The incidence of AIDS and HIV infection varies widely among the states. Since the focus of this paper is the implementation of HIV consortia programs funded by Title II during 1995, state-level AIDS rates per 100,900 population for 1995 were used to put state-level policies for Title II consortia into the context of the incidence of AIDS. The map for male adults/adolescent AIDS annual rates was used for this study to present the incidence of AIDS throughout the United States, with each state assigned to one of our four AIDS-incidence categories." To illustrate the incidence of AIDS throughout the United States, the states were classified according to reported cases: highest incidence of AIDS (75 or more AIDS cases per 100,000 population); high incidence (50 to 74.9 AIDS cases per 100,000 population); medium incidence (25 to 49.9 AIDS cases per 100,000 population) or low incidence (0 to 24.9 AIDS cases per 100,000 population). Table 2-I summarizes the categorization of the states by the incidence of AIDS.

Table 2-I:
Categorization of the States by AIDS Incidence Rates for Males (1995)

LOW INCIDENCE (Less than 25.0 cases per 100,000 population): Alaska, Arkansas, Idaho, Iowa, Indiana, Kentucky, Maine, Minnesota, Montana,Nebraska, New Hampshire, New Mexico, North Dakota, Ohio, Oklahoma, South Dakota, Utah, Vermont, West Virginia, Wisconsin, and Wyoming.

MEDIUM INCIDENCE (25 - 49.9 cases per 100,000 population): Alabama, Arizona, Colorado, Illinois, Kansas, Massachusetts, Michigan, Mississippi, Missouri, North Carolina, Oregon, Pennsylvania, Rhode Island, Tennessee, Virginia, and Washington.

HIGH INCIDENCE (50 - 74.9 cases per 100,000 population): Georgia, Hawaii, Louisiana, Nevada, South Carolina, and Texas.

HIGHEST INCIDENCE (75 and over cases per 100,000 population): California, Connecticut, Delaware, District of Columbia, Florida, Maryland, New Jersey, and New York.

Survey Results: HIV Consortia Characteristics

Within broad guidelines specified in the CARE Act, the states were given flexibility in determining the number of consortia to create and the geographic areas of the states each would serve, although states were required to balance the service needs of areas with high and increasing incidence of HIV with the service needs of rural areas." The survey of the AIDS program directors asked how many Tie II HIV consortia operated within their states during 1995. As Table 2-2 illustrates, the number of consortia ranged from one in a number of states to as high as 44 in California. The questionnaire also asked how the number of Tile II HIV consortia operating during 1995 compared to the number operating during 1994. As Table 2-2 presents, almost all states reported that the number of HIV consortia operating during 1995 either remained the same or increased when compared to 1994. In addition, the questionnaire asked the AIDS program directors to estimate how the number of HIV consortia expected to operate in 1996 compared to the number operating in 1995. All states reported that the number of Tile II HIV Consortia was expected to remain the same in 1996. (Given the consistency of responses, these 1996/1995 comparison data are not reported in Table 2-2).

The questionnaire asked if any Title II HIV consortia served rural areas during 1995, with all states responding yes. The District of Columbia responded that there are no rural areas within its jurisdiction. Nevada reported that the one consortium in the state "has three sub-coalitions that address major metro and rural areas." The AIDS program director in Tennessee noted that four of the five HIV consortia in that state "cover primarily rural areas."

Table 2-2
HIV Consortia Funded by Tile II of the Ryan White CARE Act during 1995:
HIV Consortia Characteristics

	The Number of HIV Consortia During 1995 was:	The Number of HIV Consortia in 1995 Compared to 1994	During 1995 Service Priorities for HIV Consortia Were Established at:
Alabama	a	increased in 1995	local level
Alaska	3	remained the same	local level
Arizona	5	decreased in 1995	local level
Arkansas	5	remained the same	local level
California^	44	increased in 1995	local level
Colorado	5	remained the same	state level
Connecticut^	9	increased in 1995	state and regional level
Delaware	1	remained the same	state level
District of Columbia^	1	remained the same	"D.C. is both state and local level."
Florida^	12	remained the same	local level
Georgia	16	remained the same	local level
Hawaii	1	remained the same	state level
Idaho	4	increased in 1995	local level
Illinois	11	increased in 1995	local level
Indiana	Indiana provides medical and support service with its Title II program but not through consortia.		
Iowa	4	remained the same	state and local level
Kansas	1	remained the same	state level
Kentucky	Kentucky does not provide consortia with its Title II program but may in the future.		
Louisiana	9	remained the same	local level
Maine	Maine does not provide consortia with its Tile II program.		
Maryland^	5	remained the same	local level
Massachusetts	21	increased in 1995	state and local level*
	'prioriiie support services through consortia at state level; prioritize which support services and how to implement them at the local level.		
Michigan	a	remained the same	local level
Minnesota	Minnesota does not provide consortia with its Tile II program.		
Mississippi	Mississippi does not provide consortia with its Tile II program.		
Missouri	3	remained the same	state and local level

Table 2-2
HIV Consortia Funded by Title II of the Ryan White CARE Act during 1995:
HIV Consortia Characteristics

	The Number of HIV Consortia During 1995 was:	The Number of HIV Consortia in 1995 Compared to 1994	During 1995 Service Priorities for HIV Consortia Were Established at:
Montana	5	remained the same	local level
Nebraska	1 - statewide 4 - regional	remained the same	local level
Nevada	1 **	remained the same	state and local level
	** The consortium in Nevada "has 3 sub-coalitions that address major metro and rural areas."		
New Hampshire	New Hampshire does not provide consortia with its Title II program.		
New Jersey^	9	remained the same	local level
New Mexico	New Mexico does not provide consortia with its Tile II program.		
New York"	17	increased in 1995	local level
North Carolina	15	remained the same	local level
North Dakota	10	remained the same	state level
Ohio	9	remained the same	local level
Oklahoma	2	increased in 1995	state and local level
Oregon	a	remained the same	local level
Pennsylvania	7	remained the same	state and local level
Rhode Island	no response to the survey		
South Carolina	9	remained the same	local level
South Dakota	South Dakota does not provide consortia with its Title II program.		
Tennessee	5	remained the same	local level
Texas	26	remained the same	local level
Utah	I- statewide	remained the same	state and local level
Vermont	1	remained the same	state level
	"Consortium has $30,000 budget, allowing it to serve as a coordinating, planning body, not direct provider of services."		
Virginia	5	remained the same	local level
Washington	17	increased in 1995	local level
West Virginia	1	remained the same	local level
Wisconsin	9	remained the same	state and local level
Wyoming	"No true consortia in Wyoming. Our best effort has produced only a network. The lead agency is the Health Department. We pay the bills individually as they are forwarded by case managers."		

*States with the highest incidence of AIDS.

Source: Robert J. Buchanan, Ph.D., Department of Community Health, University of Illinois, a 1995 survey of state program administrators, Title II of the Ryan White CARE Act. This research was funded by a grant from the Health Care Financing Administration, U.S. Department of Health and Human Services (grant # 16-P-90266/5-01).

The CARE Act allowed flexibility to establish service priorities for the Title II HIV consortia at either the state, regional or local levels.'* The questionnaire asked at which of these levels were service priorities of consortia established during 1995, with the questionnaire providing the following options for responses: state level, local level, other (please describe). As Table 2-2 documents, most states responded that services prioritiesfor Title II HIV consortia were established at the local level during 1995.

Survey Results: HIV Consortia Services

The CARE Act specifies that HIV consortia coordinate a continuum of outpatient health and related support services.[13] Given the flexibility the CARE Act gives to the state Title II programs to establish services prioriiies (see Table 2-2), the questionnaire asked the AIDS program directors to provide the services offered by HIV consortia during 1995. To facilitate responses, the questionnaire offered a listing of 20 medical and support services along with a response of "other (please describe)," with a request to circle any that apply. The 20 medical and support services listed on the questionnaire are:

medical care	nursing care	dental care
mental health counseling	substance abuse services	home health services
homemaker services	adult day care	respite care
hospice care	transportation services	benefits advocacy
home-delivered meals	case managers	housing referrals
HIV support groups	child care services	legal services
personal care	podiatry services	other (please describe):

The medical and support services provided by the Title II HIV consortia in the states and the District of Columbia are summarized in Table 23. In addition to the 20

Table 2-3
HIV Consortia Funded by Title II of the Ryan White CARE Act during 1995:
HIV Consortia Services

	The HIV Consortia Services Funded by Title II in 1995:	The Most Effective Consortia Services that Meet the Health Care Needs of People with HIV:
Alabama	mediil care. mental health counseling, home-delivered meals, HIV support groups, personal care, nursing care, transportation services, case managers, dental care, home health services, respite care, housing referrals, legal services, nutrition supplements, medications, and financial assistance	case management and medical and personal care
Alaska	payment for medical care, mental health counseling, home-delivered meals, HIV support groups, transportation services, case mar&e&dental care, and benefits advocacy	case management
Arizona	medical care. mental health counseling, homemaker services, HIV support groups. personal care, nursing care, transportation services, case managers, dental care, home health services, respite care, benefits advocacy, housina referrals. legal services nutritional assessments. nutritional supplements, medii (not on state program), and durable medical equipment	primary medical care, dental care, and home health services
Arkansas	madiil care, mental health counseling, substanca abuse services, transportation services, case managers, dental care, benefits advocacy, housing referrals, legal services, and direct financial assistance	case management
California^	Varies among the 44 consortia. "Collectively all if not most services are covered by consortia."	noanswar
Colorado	medical care, mental health counseling, homemaker services, hospice care, homadeliied meals, HIV support groups, personal care. nursing care. substance abuse services, transportation services, case managers, dental care, home health services, and respite care	'Primary medii care and dental care [are] available to clients via voucher programs and emergency financial assistance"
Connecticut^	medical care, mental health counseling, homemaker services, home-delivered meals, HIV support groups, personal care, substance abuse services, transportation services, case managers, child care services, podiatry services, dental care, home health services, respite care, benetits advocacy, housing referrals. and legal services	case management services, transportation, services, client special care fund and primary health care fund
Delaware^	mental health counseling, home-delivered meals ("meals on site"), HIV support groups, substance abuse services, transportation services, case managers, child care services, support services, buddy services, congregate meals, food bank, and nutritionist services transportation, HIV support groups. and complementary therapies.	HIV support groups, buddy programs, transportation, and support
District of Columbia^	case managers, housing referrals, home care coordination	(#1) AIDS Drug Assistance Program (#2) case management services
Florida^	medical care, mental health counseling, homemaker services, hospice care (in home), home delivered meals, HIV support groups, personal care. nursing care, substance abuse services, transportation services, case managers, podiatry services, dental care, home health services respite care, benefits advocacy, housing referrals (case mgt.), pharmaceuticals, child care	'A single service cannot be identified as such. It is the continuum of care that makes Title II effective - the broad array of services covered [in Florida]".
Georgia	mediil care, mental health counseling, hospice care, HIV support groups, nursing care, substance abuse services, transportation services, case managers. dental care. home health services, benefits advocacy, and housing referrals	medical services
Hawaii	mediil care, mental health counseling, homemaker services, hospice care. home-delivered meals, HIV support groups, personal care, nursing care, substance abuse services, adult day care. transportation services, case managers. child cam. podiatry services, dental care, home health &vices, respite care. benetits advocacy, housing referrals, and legal services	no answer
Id[redacted]	medical care, mental health counseling, homemaker services. hospice cam. home-delivered meals, HIV support groups, personal care. nursing care, substance abuse services, adult day care, transportation services, case managers, child care, podiatry services, dental care, home health services, respite care, (depending on the consortia)	direct medical care
Illinois	medical care, mental health counseling, homemaker services, home-delivered meals, HIV support groups, substance abuse services, transportation services, case managers, child care servims, dental care, home health services, benefits advocacy, housing referrals, legal services, rent assistance, and assistance with telephone/utility bills	no answer
Indiana	Indiana provides medical and support service with its Title II program but not through consortia.	
Iowa	mental health counseling, home-delivered meals, HIV support groups, personal care, transportation services, case managers, dental care, benefits advocacy, medical care, buddy services, housing referrals, and legal services	case management, drug assistance, housing assistance, and emergency financial services
Kansas	mediil care, mental health counseling, homemaker services, hospice care, HIV support groups, personal care. nursing care. substance abuse services, adult day care, transportation services, case managers, dental care, home health services, respite care, and housing referrals	case management and drug reimbursement
Kentucky	Kentucky does not provide consortia with its Title II program but may in the future.	

Table 2-3
HIV Consortia Funded by Title II of the Ryan White CARE Act during 1995:
HIV Consortia Services

	The HIV Consortia Services Funded by Title II in 1995:	The Most Effective Consortia Services that Meet the Health Care Needs of People with HIV:
Louisiana	emergency assistance, legal advocacy, volunteer services, case management, transportation, and food pantry	all
Maine	Maine does not provide consortia with its Title II program.	
Maryland^	medical care, mental health counseling, home-delivered meals, HIV support groups, substance abuse services, transportation services, case managers, child care services, dental care, respite care, benefits advocacy, and legal services	primary care
Massachusetts	mental health counseling, home-delivered meals, HIV support groups, personal care, substance abuse services, adult day care, transportation services, case managers, child care services, respite care, benefits advocacy, housing referrals, and legal services	no answer
Michigan	medical care, mental health counseling, homemaker services, home-delivered meals, HIV support groups, personal care, nursing cm, substance abuse services, transportation services, case managers, dental care, home health services, respite care, and benefits advocacy	case management
Minnesota	Minnesota does not provide consortia with its Title II program.	
Mississippi	Mississippi does not provide consortia with its Title II program.	
Missouri	medical care, mental health counseling, homemaker services, HIV support groups, personal care, nursing care, substance abuse services, transportation services, case managers, dental care, home health services, benefits advocacy, housing referrals, nutrition supplements, and chiropractic service	service coordination, home health, and medications
Montana	medical care, mental health counseling, substance abuse services, case managers, dental care, and pharmaceuticals not covered by drug assistance program	case management, pharmaceuticals, and medical care
Nebraska	medical care, mental health counseling, transportation services, case managers, dental care, home health services, and housing assistance	medical and dental care and housing assistance
Nevada	medical care, mental health counseling, homemaker services, home-delivered meals, HIV support groups, personal care, substance abuse services, adult day care, transportation services, case managers, dental care, home health services, respite care, benefits advocacy, housing referrals, legal services, hospital visitation, housing assistance subsidies, emergency financial assistance, nutritional supplements & counseling, and translation services	transportation, nutritional supplements, housing assistance, support groups, counseling services, and case management
New Hampshire	New Hampshire does not provide consortia with its Title II program.	
New Jersey^	medical care, mental health counseling, hospice care, home-delivered meals HIV support groups, personal care, nursing care, substance abuse services, transportation services, case managers, child care services, dental care, respite care, benefits advocacy, housing referrals, and legal services	"HIV early intervention services in various clinical settings, i.e., hospitals, local health departments, federally-funded primary care centers and drug treatment centers."
New Mexico	New Mexico does not provide consortia with its Title II program.	
New York^	medical care, mental health counseling, homemaker services, home-delivered meals, HIV support groups, personal care, substance abuse services, adult day care, transportation services, case managers, dental care, benefits advocacy, housing referrals, legal services, and information and referral	HIV primary care, dental care med./pharm., home care, day health care, mental health services, case management, nutrition/food, substance abuse services, transportation
North Carolina	medical care, mental health counseling, homemaker services, hospice care, home-delivered meals, HIV support groups, personal care, nursing care, substance abuse services, adult day care, transportation services, case managers, child care, podiatry services, dental care, home health services, respite care, benefits advocacy, housing referrals, and legal services	case management, in-home care, and transportation
North Dakota	medical care, mental health counseling, personal care, nursing care, case managers, podiatry services, dental care, home health services, and respite care	drug reimbursement
Ohio	medical care, mental health counseling, homemaker service, hospice care, home-delivered meals. housing assistance. nursing care, substance abuse services, transportation services, child care, dental care. home health services, respite care, housing referrals, legal services, child welfare and family services, nutrition, rehabilitation services, and diagnostic and monitoring	homemaker, home health aide, housing assistance. and nutrition assistance

Table 2-3
HIV Consortia Funded by Title II of the Ryan White CARE Act during 1995:
HIV Consortia Services

	The HIV Consortia Services Funded by Tii II in 1995:	The Most Effective Consortia Services that Meet the Health Care Needs of People with HIV:
Oklahoma	medical care, mental health counseling. HIV support groups. transportation services, case managers, dental care, benefits advocacy, housing referrals, nutritional care. outreach services. and information & referrals	case management
Oregon	medical care, mental health counseling, hospice care (residential), home-delivered meals, HIV support groups, personal care, nursing care, substance abuse services, adult day care, transportation services, case managers, dental care, respite care, benefits advocacy, housing referrals, adoption/foster care, and buddy/companion services	medical care, case management, counseling, and client advocacy
Pennsylvania	medical care, mental health counseling, hospice care, HIV support groups, nursing care, substance abuse services, transportation services, case managers, home health services, benefits advocacy, legal services, and emergency assistance	case management services
Rhode Island	no response to the survey	
South Carolina	medical care, mental health counseling, homemaker services, home-delivered meals, HIV support groups, personal care. nursing care, substance abuse services, adult day care. transportation services, case managers, dental care, home health services, respite care, benefits advocacy, housing referrals, and legal services	medical care ("Nine outpatient clinics have been established in South Carolina with Iii II funds.')
South Dakota	South Dakota does not provide consortia with its Title II program.	
Tennessee	limited medical care, mental health counseling, homemaker services, hospice care, personal care, nursing care, substance abuse services, adult day care. transportation services, case managers. child care, dental care, home health services, respite care. benefits adwcacy, and nutritional services	case management in rural areas. nutritional services, and day care
Texas	medical care, mental health counseling. homemaker services. hospice care, home-delivered meals, HIV support groups, personal care, nursing care, substance abuse services, adult day care, transportation services, case managers, child care, podiatry services, dental care. home health services, respite care, benefits advocacy, housing referrals, and legal services	health insurance continuation program
Utah	mental health counseling. substance abuse services. transportation services. case managers. education, housing, nutrition, dental care, benefits advocacy, legal services medications, and vision care	dental. lab. and mental health counseling
Vermont	"Consortium has $30,000 budget allowing it to serve as a coordinating, planning body, not direct provider of services."	
Virginia	medical care, mental health counseling, hospice care, home-delivered meals, HIV support groups, personal care, nursing care, substance abuse services, transportation services, case managers, child care, dental care, home health services, respite care, benefits adwcacy, housing referrals, and legal services	primary medical care
Washington	medical care, mental health counseling. homemaker services, hospice care, home-delivered meals, HIV support groups, adult day care, transportation services, case managers, child care services, dental care, and housing referrals	no answer
West Virginia	medical care, mental health counseling, homemaker services, hospice care, home-delivered meals, personal care, nursing care, transportation services, case managers, child care, dental care, home health services, respite care, benefits advocacy, housing referrals, and legal services	medications not covered by the Title II drug assistance program
Wisconsin	medical care, mental health counseling, homemaker services, home-delivered meals, HIV support groups, personal care. substance abuse services, transportation services, case managers, child care dental care, home health services, respite care, benefits advocacy, housing referrals, and legal services	case management, housing, and HIV early intervention
Wyoming	"No true consortia in Wyoming. Our best effort has produced only a network. The lead agency is the Health Department. We pay the bills as they are forwarded by case managers."	

^States with the highest incidence of AIDS.

Source: Robert J. Buchanan, Ph.D., Department of Community Health, University of Illinois, a 1995 survey of state program administrators, Title II of the Ryan White CARE Act. This research was funded by a grant from the Health Care Financing Administration, U.S. Department of Health and Human Services (grant # 18-P-90286/5-01).

medical and support services provided on the questionnaire, a number of states reported coverage of other consortia services. Among these other medical and support services provided by HIV consortia during 1995 were: nutrition supplements and counseling, medications, financial assistance, durable medical equipment, buddy/companion services, home care coordination, child care, assistance with rent and utilities bills, chiropractic services, translation services, outreach services, information referrals, adoption/foster care, lab services, and vision care.

The questionnaire also asked the AIDS program directors of all the services provided by HIV consortia in their states during 1995, to "list the most effective of meeting the health care needs of people with HIV." Table 2-3 presents the responses. Among the effective consortia services mentioned most often are: case management, primary medical care, drugs/medication, dental care, and home care. However, as the response from Florida summarized: "a single service cannot be identified as [most effective]. It is the continuum of care that makes Tile II effective - the broad array of services covered [in Florida]." The services identified in Table 2-3 offer examples to the HIV consortia funded by Title II of the broad array of medical and support services that comprise the continuum of care needed by people with HIV illness.

Survey Results: Title II Beneficiaries and Eligibility Policies

The CARE Act did not establish income restrictions for individuals to receive benefits from Tile II programs, although the statute did specify that CARE Act programs must be the payer of last resort.[14] Given the absence of federally-set income standards for eligibility, the states have the ability to establish there own financial eligibly criteria for individuals to receive Tile II benefits. The survey asked the AIDS program directors to provide: the number of people receiving benefits from HIV

consortia; medical and financial eligibility criteria for HIV consortia; spend down procedures for eligibility; and any use of waiting lists.

People Receiving HIV Consortia Benefits

The questionnaire asked the AIDS program directors to estimate at the time of the survey (mid 1995) the number of people receiving benefits from HIV consortia funded by Title II, with these estimates presented in Table 2-4. The questionnaire also asked the AIDS program directors to estimate how the number of people receiving HIV consortia benefits in 1995 compared to the number of people receiving these benefits in 1994. All of the states (and the District of Columbia) responding to survey reported that the number of beneficiaries increased in 1995 except for six states. Alaska, Montana, Vermont[b], and Virginia reported that the number of beneficiaries remained the same, New Jersey reported the number of beneficiaries decreased in 1995, and Michigan reported that these data were not available. (Given the similarity of responses from most states, these data are not reported in Table 2-4.) In addition, the questionnaire asked the AIDS program directors to estimate how the number of people receiving consortia benefits in 1995 compared to the number of people expected to receive these benefits during 1996. All of the states (and the District of Columbia) reported that the number of beneficiaries expected to receive HIV consortia benefits will increase in 1996, except for Arizona, California (if funding is stable), Montana, Utah (probably), and Washington state which expect the number of beneficiaries to remain the same during 1996. (Again, these data are not reported in

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[b]Vermont reported that there were no beneficiaries receiving benefits from HIV consortia funded by Title II during 1995. The survey response from Vermont included that the "consortium has a $30,000 budget, allowing it to serve as a coordinating, planning body, not a direct provider of services."

Table 2-4
HIV Consortia Funded by Title II of the Ryan White CARE Act during 1995:
Beneficiaries and Eliiibilii Policies

	Estimates of the Number of People Receiving Benefits From HN Consortia Funded by the Tiie II Program:		Medical Eligibiiii Requirements for HIV Consortia	To be Financially Eligible for HN Consortia, Gross Monthly Income during 1995 Cannot Exceed:		Compared to 1993, Financial Eligibility Criteria for HIV Consortia in 1995 Became:	Do HIV Consortia Eligibiiii Determination Procedures Include Spend Down?
	1995	1995 Compared to 1994		1-Person Household	4-Person Household		
Alabama	7 0 0	increased in 1995	HN+	no income requirements	no income requirements	not applicable	not applicable
Alaska	200	remained the same	HN+	not specified - "low income"	not specified - "low income"	more restrictive in 1995	no
Arizona	1,500	increased in 1995	HIV+	no income standard	no income standard	remained the same	no
Arkansas	1,155	increased in 1995	HN+	$12,580/year	$25,520/year	remained the same	yes
California^	27,430 (estimate)	increased in 1995	•		•	varies among the 44 consortia and the services funded	no answer
	"Minimum requirement: indiiuals or family members of individuals with HIV/AIDS; other requirements may vary among the 44 consortia. Financial eligibility criteria vary among the 44 consortia and the services funded."						
Colorado	4.000	increased in 1995	HIV+; consortia may requireT-Cells <300	varies with service**	varieswith service"	less restrictive in 1995	varies with service**
	**"Individual income levels'can vary from $600/month [$1,200/month for a family of 4] for the food bank to $1,840/month [$3,700/month for a family of 4] for the insurance continuation program.' There is spend down for the food bank but not for the insurance program.						
Connecticut^	1.150	increased in 1995	HIV+	$1,245/month (200% of poverty level)	$2,525/month	less restrictive in 1995	yes
Delaware	705	increased in 1995	HN+	$613.33/month	$2,281/month	more restrictive in 1995	no
District of Columbia^	1,282	increased in 1995	HIV, AIDS, or related illness	all income levels served	all income levels served	remained the same	not applicable
Florida^	12,641	increased in 1995	HIV+	Each consortium sets eligibility for their respective areas		remained the same	Each consortium sets eligibility for their area
Georgia	4,000	increased in 1995	diagnosis of HIV disease	185% of federal poverty level	185% of federal poverty level	remained the same	yes
Hawaii	570	increased in 1995	HIV+	300% of poverty level	300% of poverty level	remained the same	no
Idaho	100	increased in 1995	HIV+ & CD4<500	400% of poverty level	400% of poverty level	remained the same	no
Illinois	4,000	increased in 1995	HIV+ or AIDS	$14,940/year	$30,300/year	remained the same	no
Indiana	Indiana provides medical and support services with its Title II program but not through consortia.						
Iowa	6 4 4	increased in 1995	HN+	$1,246/month	$2,525/month	remained the same	no
Kansas	200	increased in 1995	HIV+	$1,840/month	$3,700/month	less restrictive in 1995	no
Kentucky	Kentucky does not provide consortia with its Title II program but may in the future.						
Louisiana	3,500	increased in 1995	HIV+	200% of poverty level	200% of poverty level	stable	no
Maine	Maine does not provide consortia with its Title II program.						
Maryland^	4,866	increased in 1995	HIV+	State sliding scale fee, but no one denied service for inability to pay.		remained the same	yes
Massachusetts	4,000	increased in 1995	HIV+	no income requirements	no income requirements	no income requirements	not applicable
Michigan	4,000	data not available	all HIV+ eligible	no income requirements	no income requirements	more restrictive since 1992 with DAP	no
Minnesota	Minnesota does not provide consortia with its Title II program.						
Mississippi	Mippi does not provide consortia with its Title II program.						
Missouri	1,471	increased in 1995	HN+	$2,500/month	$5,000/month	less restrictive in 1995	no
Montana	75	remained the same	HIV+, CD4<500	$623/month (for full coverage)	$1,263/month (for full coverage)	remained the same	no
Nebraska	1 8 3	increased in 1995	HN+	$1,245/month	$15,480/year	remained the same	yes

Table 2-4
HIV Consortia Funded by Title II of the Ryan White CARE Act during 1995:
Beneficiaries and Eliiibiiii Policies

	Estimates of the Number of People Receiving Benefits From HIV Consortia Funded by the Title II Program:		Medical Eliiibilii Requirements for HIV Consortia	To be Financially Eligible for HIV Consortia, Gross Monthly Income during 1995 Cannot Exceed:		Compared to 1993, Financial Eliiibiiii Criteria for HIV Consortia in 1995 Became:	Do HIV Consortia Eliiibilii Determination Procedures include spend Down?
	1995	1995 Compared to 1994		1-Person Household	4-Person Household		
Nevada	2.600	increased in 1995	HIV+***	***		remained the same	yes^^^
	***The "significant other or family member of person with HIV" is covered. Financial eligibilii criteria are determined by local providers.						
New Hampshire	New Hampshire does not provide consortia with its Title II program.						
New Jersey^	11.314	deceased in 1995 (reporting change)	HIV+~			remained the same	no
	~In addition to HIV+, the patient must "need medical care, have no other (or inadequate) coverage and reside" in the area of the consortium. The consortia do not set 'upper limits" for financial eligibility. "If a provider charges for services, their sliding scale fee . . . should not exceed certain proportional maximums relative to clients' income and federally established poverty levels."						
New Mexico	New Mexico does not provide consortia with its Title II program.						
New York^	70,000~	increased in 1995	HIV+ (and families for some service)	There are no financial eligibility requirements for consortia benefits		remained the same	no
	~~unduplicated count includes approximately 125,000 people reached through information and outreach services						
North Carolina	3,000	increased in 1995	HIV+ or family member	Sliding scale reimbursement		remained the same	yes
North Dakota	12	increased in 1995	no answer	no income requirements	no income requirements	less restrictive in 1995	no
Ohio	2,700	increased in 1995	HIV+	$1,374/month	$3,435/month	remained the same	yes
Oklahoma	500	increased in 1995	no answer	Documented gross income at or below 150% of federal poverty level		more restrictive in 1995	yes
Oregon	3,000	increased in 1995	HIV+	$1,441/month	$2,898/month	remained the same	no
Pennsylvania	4,591	increased in 1995	need service and no other coverage	no income requirements	no income requirements	no income requirements	no
Rhode Island	no response to the survey						
South Carolina	2,500	increased in 1995	HIV+	"Local consortia make their own decisions on financial requirements, other than patient cannot have another payment source. Most patients in S.C. are at '0' income."			
South Dakota	South Dakota does not provide consortia with its Title II program.						
Tennessee	Consortia not operational until December, 1994; in 1995 3,000+ received consortia services.		HIV+	No financial requirements have been established			
Texas	8,000	increased in 1995	HIV+	no income requirements	no income requirements	no income requirements	not applicable
Utah	455	increased in 1995	HIV+ or family member	No income limits; sliding scale fee may be imposed		remained the same	no
Vermont	0~~~	remained the sam	not applicable~~~	not applicable~~~	not applicable~~~	not applicable~~~	not applicable~~~
	~~"Consortium has $30,000 budget, allowing it to serve as a coordinating, planning body, not direct provider of services."						
Virginia	2,000	remained the same	HIV+	$1,245/month	$2,525/month	remained the same	no
Washington	1,600	increased in 1995	HIV+ ("for some services: caregivers and loved ones")	No financial eligibility standards			no
West Virginia	425	increased in 1995	HIV+	$1,300/month	$5,200/month	remained the same	no
Wisconsin	500-700	increased in 1995	HIV+ & depends on scope & type service	depends on service		remained the same	no
Wyoming	"No true consortia in Wyoming. Our best effort has produced only a network. The lead agency is the Health Department. We pay the bills indiiually as they a&forwarded by case managers."						

^States with the highest incidence of AIDS.

Source: Robert J. Buchanan, Ph.D., Department of Community Health, University of Illinois. a 1995 survev of state program administrators, Title II of the Ryan White CARE Act. This research was funded by a grant from the Health Care Financing Administration, U.S. Department of Health and Human Services (grant # 18-P-90286/5-01).

Table 24 due to the similarity of responses from the states.)

Medical Eligibility Requirements

The questionnaire asked the AIDS program directors to provide medical eligibility requirements for people to receive benefits from HIV consortia funded by Tile II during 1995. As the Table 24 illustrates, most states responded that the individual must be HIV positive to meet medical eligibility requirements. In Montana and Idaho an individual must be infected with HIV and also have a CD4 count below 500, while in Colorado consortia may require a count below 300. In addition, California, Nevada, North Carolina, Utah, and Washington state (for some services) noted that family members or other people also may receive HIV consortia benefits (see Table 24 for the responses from these states).

Income Eligibility Requirements

The questionnaire asked the AIDS program directors to provide the maximum monthly income level an individual in a one-person household could have during 1995 to be eligible for HIV consortia services. In addition, the AIDS program directors were asked to provide the maximum monthly income a family of four could have during 1995 for an individual within that family to be eligible for HIV consortia services. These financial eligibility requirements reported by the states are presented in Table 24. A number of states reported no income requirements for HIV infected people to receive benefits from HIV consortia funded by Title II.

As Table 24 illustrates, even states that establish income ceilings for eligibility for services provided by HIV consortia set generous eligibility standards. This is particularly noticeable if income eligibility standards for benefits from HIV consortia funded by Title II are compared to income eligibility standards for state Medicaid

coverage (the largest payer of AIDS-related care.) For example, during 1993 most individuals with AIDS could not have incomes in excess of $434 per month to receive Medicaid coverage in most states." Hence, HIV consortia funded by Title II can provide services to people infected with HIV who have incomes too high to become eligible for Medicaid coverage. The Title II programs strengthen the public-sector safety net for funding the care needed by people with HIV-related illness.

The questionnaire asked if financial eligibility criteria for services provided by HIV consortia during 1995 have become more restrictive since 1993, providing responses of "more restrictive in 1995," less restrictive in 1995," or "remain the same." While financial eligibility for HIV consortia funded by Title II remained the same in most states, these criteria have changed in a number of states as Table 2-4 illustrates. The questionnaire also asked the AIDS program directors if they expected financial eligibility criteria for HIV consortia to become more restrictive during 1996. All the states (and the District of Columbia) responding to the survey that provided Title II consortia programs reported that financial eligibility criteria are expected to remain the same during 1996 except for five states.[c] Financial eligibility criteria for HIV consortia in Florida, Michigan, Missouri, and Nebraska are expected to become more restrictive in 1996 and less restrictive in North Carolina. (Given the similarity of responses from most states, these data for 1996 are not reported in Table 2-4.)

Spend Down Procedures

The questionnaire asked the AIDS program directors if eligibility determination procedures for benefits provided by HIV consortia funded by Title II include a spend

[c]In addition, the Title II coordinators from California and South Carolina responded that local consortia establish their own financial eligibility criteria.

down provision. Spend down was defined on the questionnaire as "allowing the applicant to deduct the cost of medical care from income levels and using this medical-cost adjusted income level for eligibility determination." (Most state Medicaid programs allow spend down when determining Medicaid eligibility?) As Table 2-4 documents, a number of states include spend down provisions in the determination of financial eligibility for benefits provided by HIV consortia funded by Tile II.

Waiting Lists

The questionnaire asked if there was a waiting list of people in their state waiting to receive benefits from HIV consortia funded by Title II during 1995. If there was a waiting list, the AIDS program directors were asked to estimate both the number of people currently on the waiting list at the time of the survey and the number of days a person had to wait to receive benefits during 1995. Based on the survey responses, only the Title II program in Nevada (with the use of waiting list varying by provider and no statewide list) reported waiting lists for HIV consortia services. (Given the absence of reported waiting lists in all other states, these data are not reported in Table 2-4.)

Coordination with Medicaid

Although the CARE Act specifies that Title II funds must be the payer of last resort, Title II programs can supplement Medicaid coverage if Medicaid does not cover a needed health. service or if a recipient's care needs exceed Medicaid utilization limits. The state Medicaid programs and Title II programs can coordinate services to provide a continuum of care and eliminate duplication of services, serving the care needs of people with HIV diseases more efficiently.[17 18] A study by the National Governor's Association (NGA) examined how the state Medicaid programs and programs funded

by Tile II can coordinate to serve people with HIV and AIDS more effectively and efficiently.[19] Among the areas of collaboration identified by the NGA study are: planning and implementing home care services; administering drug reimbursement and assistance programs; administering health insurance continuation programs; cross-training between CARE Act and Medicaid programs; sharing information and protecting client confidentiality; planning, administering and staffing case management services; collaborating through CARE Act program meetings (e.g., Title II statewide advisory committees); and outstationing Medicaid eligibility workers.

Title II/Medicaid Utilization Limits

The questionnaire asked the AIDS program directors if the Medicaid program in their state "limits utilization of outpatient and home-based care (e.g., 18 physician visits per year or 50 home health visits per year), do HIV consortia funded by Tile II in your state cover the use of these services in excess of the Medicaid limits?" To facilitate responses, the questionnaire provide "yes," "no," and "no Medicaid utilization limits" as possible responses. As Table 2-5 documents, HIV consortia funded by Title II in many states did not cover needed services in excess of Medicaid utilization limits.

Effective Title II /Medicaid Coordination

The questionnaire asked the AIDS program directors to "describe effective methods and policies for the coordination and integration of the Medicaid program with the Title II program in your state." As Table 2-5 indicates, many AIDS program directors repotted'that Medicaid representatives serve on Title II boards or committees, as well as conducting joint meetings on policy development and

Table 2-5
HIV Consortia Funded by Tii II of the Ryan White CARE Act during 1995:
HIV Consortia and Medicaid

	Do HIV Consortia Cover the Use of Services When Need Exceeds Any Medicaid Limits?	Effective Methods and Policies for the Coordination of Medicaid and Title II of the Ryan White CARE Act	Barriers to the Coordination and Integration of Mediiid and Tii II of the Ryan White CARE Act
Alabama	no answer	=A representative for Medicaid sits on our advisory board.'	HCFA confidentiality requirements
Alaska	no	"Work closely with Medicaid to try to qualify o l i i . Don't cover any service with Title II that Medicaid covers.'	works o.k.
Arizona	yes	no answer	AHCCCS [Medicaid] has numerous plans with different benefits. Determination of eligibility time-consuming and difficult."
Arkansas	yes	'All clients apply for Medicaid when enrolled in the consortia program. . . . If eligible, the most expensive drugs needed are put on the Msdiiid card" and Tii II pays for the rest.	not applicable
California^	no answer	no answer	no answer
Colorado	no Medicaid utilii limits	Informal interaction between Title II and Medicaid stags; these stags share many committee assignments. Title II insurance oontinuatlon program run by staff that administers Medicaid.	"Distance is always a problem in outstate areas of Colorado. Travel time and lack of trawl reimbursement prevent staff from meeting with Title II providers in committees and consortia meetings.'
Connecticut^	"It varies across providers."	"We do not currently have these in place." ("An HIV Medicaid managed care plan has been drafted.")	'Programs are managed by different state agencies. There is no federal/state dirsctivs or mandate to facilitate this [coordination]."
Delaware^	no	quarterly meetings and E-mail	none
District of Columbia^	yes	Medicaid database terminal provided at cost to prevent duplication of services and provide case managers with Medicaid eligibility data.	"The Mediiid applii process is extremely time consuming and frustrating for many clients and case managers. Efforts to ensure that dii utilii Mediiid are often unsuccessful because Title II services are more comprehensive and accessible. Also, service providers [prefer Title II funding which has a more] reliable payment schedule . . .
Florida^	yes ("As last resort, Title II will cover these services.")	"Case management agencies throughout Florida are kay entry pcints for Title II services. Case managers assist clients in navigating and obtaining the appropriate services, like Medicaid. They also ensure Title II is payor of last resort."	'Administration of ths Msdiiid program is ths responsibility of a separate state agency from the agency that is the Title II grantee. This situation makes coordination diilt at times. Sut coordinated meetings and cross-training opportunitii have been helpful.'
Georgia	not applicable	none rnentionsd	none mentioned
Hawaii	no Medicaid utilii limits	'In addition to official coordination between the Hawaii State Department of Health and ths Hawaii Mediiid progmm, staff from [Medicaid] serves on the Ryan White consortium's board of directors and on the consortium's Ryan Whiie Oversight Committee	no answer to the question
Idaho	not sure	"We are working at improving oocrdination between state Medicaid and Ryan Whiie.	noanswertothequestion
Illinois	no	"Individuals receiving Medicaid are not eligible for Title II funded services unless they are non-Medicaid reimbursable. Case managers assist dii in determining Medicaid eligibilii and applying for benefits. A [Medicaid] representative is seated on the Department's Title II Advisory Committee.'	"The Mediiid program is administered by a different state agency.'

Table 2-5
HIV Consortia Funded by Tii II of the Ryan White CARE Act during 1995:
HIV Consortia and Medicaid

	Do HIV Consortia Cover the Use of Services When Need Exceeds Any Medicaid Limits?	Effective Methods and Policies for the Coordination of Medicaid and Tii II of the Ryan White CARE Act	Banters to the Coordination and Integration of Medicaid and Title II of the Ryan White CARE Act
ıdiana	Indiana provides medical and support service with its Title II program but not through consortia.		
Iowa	yes	"Joint meetings on policy and coordination; developing policy together.	"Confidentiality - sharing information between the two programs.
ansas	yes	"This is not a problem. In a small state we tend to work together without a formal requirement.	no answer to the question
entucky	Kentucky does not provide consortia with its Title II program but may in the future.		
wisiana	varies	'Ryan White is the payer of last resort..	none mentioned
laine		Maine does not provide consortia with its Title II program.	
Maryland^	"Only home-based care is limited; we cover services in excess of limits.	"Medicaid staff participate in Maryland AIDS Policy Workgroup; Tii II vendors are required to be approved as Medicaid providers and must till [Medicaid] for covered services; Title II staff also provide AIDS-related expendire analyses for Medicaid, are developing a cooperative quality assurance program, and are working with Medicaid HMO staff in training and delivery issues.'	none
lassachusetts	"The use of appropriate consortia services is allowed if Medicaid limits are encountered.'	"Coordination between Mass. D.P.H. and the state Medicaid program through joint planning and program administration."	noanswertothequestion
lichigan	• It varies across providers."	"DSS has designated an AIDS Coordinator to help with the coordination and integration of DSS and MDPH care services. The DSS coordinator as well as MDPH sits on the Title I Planning Council and Tii II consortia."	no answer to the question
innesota	linnesota does not provide consortia with its Tii II program.		
ississippi		ississippi does not provide consortia with its Title II program.	
Missouri	yes	"Medicaid AIDS waiver services is the best example.'	"Medicaid applii process.
Mmltana	noanswertothequestion	• clii may be accepted [by Tii II] on provisional basis but must apply for and be declared ineligible for Medicaid within 90 days.'	noanswartothequestion
ebraska	yes	Ryan White is payer of last resort	no answer to the question
evada	yes	"We share an online electronic verification of eliiibilii system: the state Medicaid AIDS Coordinator is an ad hoc member of the statewide Tii II consortium and the state AIDS Task Force.'	"Barriers center around the lack of a [Medicaid] waiver for PWA and poor [Medicaid] hospice coverage.

Table 2-5
HIV Consortia Funded by Tii II of the Ryan White CARE Act during 1995:
HIV Consortia and Mediikl

	Do HIV Consortia Cover the Use of Services When Need Exceeds Any Medicaid Limits?	Effective Methods and Polii for the Coordination of Medicaid and Title II of the Ryan White CARE Act	Barriers to the Coordination and Integration of Medicaid and Title II of the Ryan White CARE Act
New Hampshire	New Hampshire does not provide consortia with its Title II program.		
New Jersey^	"Case by case basis; if Medicaid places a limit on a needed service, it is possible that Title II consortia will cover those services."	"The most effective methods ... for coordination occur outside [Title II] ... consortia component. The [Title II] HIV Home Care program fills the gaps for clients before qualifying for Medicaid and for [services] above Medicaid limits .... [Title II] AIDS Drug Assistance Program also fills gaps prior to Medicaid initiation and is administered by our Medicaid Unit within the Department of Human Services."	"One barrier is that Medicaid is not handled by the NJDHSS, but is a program of the NJDOHS. Also, at the provider level, line staff providing services are usually not the indiiuals in their institutions charged with fiscal oversight of either their project, nor of the overall HIV/AIDS work dthe institution. Therefore. coordinating the collection of comprehensive data on all HIV expenditures at an institution for a Ryan White service has been extremely difficult.
New Mexico	New Mexico does not provide consortia with its Title II program.		
New York^	no	*	**
"The State Medicaid Program is within the State Department of Social Services (SDSS). The AIDS Institute (AI) is within the State Department of Health, and it has established and ongoing working relationship with the SDSS. The AI has developed HIV-specific Medicaid rates for the provision of quality HIV services (inpatient and outpatient services, primary care in clinics and private physician offices, AIDS day health care, home care, hospice, nursing facility and case management services. **The AI has established standards of care to** ensure quality HIV services . . . **Additionally, the AI works closely with SDSS on utilization review issues to identify fraud and abuse** and on billing data for evaluation purposes. All programs are required contractually to maximii available third party reimbursement streams, specifically Medicaid and the HIV enhanced rates. The HIV Uninsured Care programs coordinate eliiibilii of participants. assist indiiuak to meet Medicaid spend down requirements, and encourage transition to Medicaid for eligible indiiuals.			
"The NYC Division of AIDS Services (DAS) limits home care reimbursement to three contractual agencies. Indiiuak served by [other] home care agencies funded by Tii II must change providers and disrupt care to transition to Medicaid [from Tii II]. An electronic eligibility verification match was recently implemented for improved efficiency in coordination with Medicaid."			
North Carolina	yes	noanswertothequestion	no answer to the question
North Dakota	yes	noanswertothequestion	noanswertothequestion
Ohio	no	"As soon as PWA are Medicaid eligible, (esp. clients in ADAP), we suggest they sign up for Medicaid. When they meet [Medicaid] spenddown or become Medicaid eligible, we have Human Services reimburse our ADAP. We have access to Human Service's data base.	"Medicaid spenddown -- temporary nature of Medicaid eligibility.'
Oklahoma	no	no answer to the question	limited Medicaid-covered services; the reorganization of the Medicaid agency in Oklahorna: and budget cuts
Oregon	yes	"Enrollment in Oregon Health Plan [Medicaid] first for more comprehensive coverage, using [Title II] to fill gaps. Offering initial anonymous HIV-related health care at local health departments, reducing need to go to a private doctor."	'Eligibility requirements for OHP [Medicaid] more stringent than [Title II]; complexity of OHP - lack of understanding, availabilii, and benefits; possible premiums and co-pays in future OHP revisions; some services not covered by OHP; and 3 months proof required to establish income level [for OHP eligibilii].'

Table 2-5
HIV Consortia Funded by Tii II of the Ryan White CARE Act during 1995:
HIV Consortia and Medicaid

	Do HIV Consortia Cover the Use of Services When Need Exceeds Any Medicaid Limits?	Effective Methods and Polii for the Coordination of Medicaid and Title II of the Ryan White CARE Act	Barriers to the Coordination and Integration d Medicaid and Tii II d the Ryan White CARE Act
Pennsylvania	not sure if there are state Medicaid utilization limits, they may do so	'Medii staff attend and participate in State HIV Planning Council and inform the Council (made up of consortia representatives) of Medicaid policies and activities that may be relevant to consortia."	"The Medicaid program is located in a different department (Department d Public Welfare).
Rhode Island	no response to the survey		
South Carolina	no Medii utilii limits ("that I know of")	'A Tii II-funded outpatient clinic at the Medii University d S.C. provides a 'seamless' transition from Title II to Medicaid when a patient becomes eligible [for Medicaid].'	"None - we work well together.
South Dakota		uth Dakota does not provide consortia with its	le II program.
Tennessee	yes	Medicaid became "TennCare in Jan., 1994. We can use [Title II] for anything not otherwise covered. The vast majority of people with HIV are eligible for [TennCare] coverage. Prior to this we had 100% of [Title II] money in drug assistance . . . "	'During early 1995 a new administration took over and the entire [Title II] program is being restructured under new directors. Thus barriers/positives are as yet unknown.'
Texas	yes	Agencies which contract for funds with the TDH are required to become a Mediiid provider for applicable program activities as required by the TDH GENERAL PROVISIONS FOR CONTRACTS, STANDARDS FOR FINANCIAL MANAGEMENT, Article 9.	"The costs associated with Medicaid provider eligibility may be detrimental to the viability of the organization presenting significant barriers to compliance with Article 9, or enforcement of Article 9 may have resulted in a loss of critical HIV/AIDS services to the community; therefore, the TDH established HIV/STD Policy 590.1 to grant waivers to the Article 9 provision upon request and verification, as well as automatic, unconditional waivers to agencies licensed as 'Special Care Facilities' or 'Special Care Hospitals'.
Utah	no Medicaid utilii limits (cost effectiveness restrictions)	There is 'not a great deal d coordination/integration" with consortium services and Medicaid.	"Medicaid has no 'mandate' to coordinate; therefore other priorities within the program take precedence."
Vermont	no Medicaid utilization limits	noanswertothequestion	no answer to the question
Virginia	yes	• Stafffrom Medicaid sit on Department d Health advisory committees.'	Service coordination, however, is adversely affected [because] Medicaid is not allowed toshareamfcliidatawith the Department d Health.
Washington	no Medicaid utilii limits	"Medicaid program staff serve on local consortia:	noansweftothequestion
Jest Virginia	no Medicaid utiliii limits	"Client must use Mediiid first. If not eligible or in spenddown, Tii II kicks in.'	none
Wisconsin	yes	Medicaid rates are used to pay for consortia services	*Separate administration: regional diierences d Mediiid programs; lag time between [Medicaid] appliiion and approval.'
Wyoming	No true consortia in Wyoming.	wr best effort nas proaucea only a network. The lead agency is the Health Department. We pay the bills as they are forwarded by case managers.	

States with the highest incidence d AIDS.

ource: Robert J. Buchanan, Ph.D., Department d Community Health, University d Illinois. a 1995 survey d state rogram administrators, Tii II dthe Ryan White CARE Ad. Thii research was funded by a grant from the ealth Care Financing Administratii. U.S. Department d Health and Human Services (grant #18-P-90286/5-01).

coordination. The response from Florida highlights the role of case management in Tile II/Medicaid coordination: "Case management agencies throughout Florida are key entry points for Tile II services. Case managers assist clients in navigating and obtaining the appropriate services like Medicaid. They also ensure that Title II is the payer of last resort."

Barriers to Title II/Medicaid Coordination

The questionnaire asked the AIDS program directors to "describe any barriers to the coordination and integration of the Medicaid program with the Tile II program in your state." As Table 2-5 presents, a number of AIDS program directors responded that administration of the two programs by different state agencies is a barrier to coordination and integration of Title II and Medicaid, although Florida noted that "coordinated meetings and cross-training opportunities have **been helpful"** in overcoming barriers caused by separate program administration. AIDS program directors in other states noted that the Medicaid eligibility/application process is difficult and time consuming. Confidentiality requirements were reported by AIDS program directors as barriers to Medicaid/Title II coordination in a number of states. For example, the response from Virginia noted that "service coordination... is adversely affected [because] Medicaid is not allowed to share any client data with the Department of Health."

Summary and Discussion

Public programs, particularly the state Medicaid programs, pay for the health services provided to most people with AIDS and a significant percentage of people infected with HIV? However, the Medicaid programs establish restrictive eligibility criteria, requiring during 1993 that incomes be below $434 per month in most

states.[21] Programs funded by the Ryan White CARE Act provide services to people with AIDS and HIV infection with higher income levels, broadening and strengthening the public-sector safety net for financing HIV-related health care. This paper focused on HIV consortia funded by Tile II of the CARE Act, presenting data on consortia characteristics, the services provided by these consortia, eligibility criteria for these services, and coordination of the HIV consortia programs with the state Medicaid programs.

The study identified a range of medical and support services that the HIV consortia funded by Tile II provided during 1995 in the various states. Among the most effective consortia services identified by the study are: case management, primary medical care, drugs/medication, dental care, and home care. However, as the response from Florida summarized: "a single service cannot be identified as [most effective]. It is the continuum of care that makes Tile II effective - the broad array of services covered [in Florida]." The services identified in Table 2-3 offer examples to the HIV consortia funded by Tie II of the broad array of medical and support services that comprise the continuum of care needed by people with HIV illness.

The study also identified the medical and financial criteria necessary for individuals to become eligible for HIV consortia services. The study documents that the state Title II programs have established generous income eligibility standards for services provided by HIV consortia, especially when compared to Medicaid eligibility standards. Hence, HIV consortia funded by Title II can provide services to people infected with HIV who have incomes too high to become eligible for Medicaid coverage. The Title II programs strengthen the public-sector safety net for funding the care needed by people with HIV-related illness.

To coordinate HIV consortia programs with the state Medicaid programs, Medicaid representatives serve on Title II boards and committees in a number of states. In addition, case managers can assist individuals who have HIV disease with the Medicaid eligibility process. This role for case managers is important because a number of state AIDS program directors identified the Medicaid eligibility/application process as a barrier to the coordination of Medicaid with the Title II programs. Another barrier to Medicaid/Title II integration and coordination mentioned by AIDS program directors in a number of states is the administrative separation of the two programs in different state agencies. Coordinated meetings and cross-training programs can help overcome the integration problems created by this separate administration of the Medicaid and Title II programs.

Generous eligibility criteria and coverage of a broad array of medical and support services by HIV consortia allow these Title II programs to strengthen the public-sector safety net for financing the care needed by people with HIV-related illness. HIV consortia funded by Title II provide needed care to people with HIV disease before they become eligible for Medicaid or Medicare.[d] Generous eligibility criteria (or no income restrictions in some states), however, can become a double-edged sword. If federal funding for Title II programs is not sufficiently increased to keep up with the increasing number of people expected to receive benefits from Title II

[d] For a person with HIV illness to become eligible for Medicare requires meeting eligibility criteria for Social Security Disability Insurance (SSDI), including disability status, sufficient work-related history, and a 29-month waiting period (5 months from disability status for SSDI payment to begin, then 24 additional months for Medicare coverage to begin). (See Baily, M., Bilheimer, L., Woolridge, J., Langwell, K., and Greenberg, W. "Economic Consequences for Medicaid of Human lmmunodeficiency Virus Infection." Health Care Financing Review (1990 Annual Supplement): 97-108.

programs, or if future federal Medicaid reform allows the states to establish even more restrictive Medicaid eligibility standards, then the Title II programs may not be able to provide services for all eligible people. This could result in the use of waiting lists, reduced services, some other forms of rationing, or the implementation of more restrictive eligibility criteria. If federal funding for Title II programs in the future does not keep pace with the expected increase in the number of people eligible for Title II services, then the public-sector safety net for financing HIV-related care will be weakened.

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5. See note 3.

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11. See note 2.

12. See note 2.

13. See note 3.

14. See note 3.

15. Buchanan, R. 'Medicaid Eligibility Pdicies for People with AIDS." Social Work in Health Care Vol.23,No.2(1996): 1541.

16. See note 15.

17. See note 3.

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21. See note 15.

Chapter 3
Drug Assistance Programs Funded by Title II of the Ryan White CARE Act[a]

Introduction

The Ryan White Comprehensive AIDS Resource Emergency (CARE) Act (Public Law 101381) was enacted in August, 1990 to improve both the quality and availability of care for people with HIV disease and their families.' The original legislation authorized: grants to metropolitan areas with the largest number of AIDS cases to help provide emergency services (Title I); grants to the states to improve the quality, availability, and organization of health and related support services (Title II); grants to state health departments for AIDS early intervention services (Title III-a) and community-based primary care facilities (Title Ill-b); and grants for research and evaluation initiatives, including demonstration programs for pediatric AIDS research (Title IV).[2] Title II of the CARE Act allows states to allocate funds among any or all of four areas to cover home-based health services, to provide medication and other treatments, to continue private health insurance coverage, or to fund HIV care consortia.[3]

Although the Ryan White legislation did not established income eligibility restrictions for people to receive CARE act services, the law did specify that CARE Act programs must be the payer of last resort.[4] However, Ryan White funds can be used to pay for care provided to Medicaid recipients if the state Medicaid program does not cover a needed health service or if a Medicaid recipient's need for a health service exceeds the Medicaid program's limits on utilization. If a state Medicaid program does

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not cover hospice care, for example, a Medicaid recipient can receive that service through a program funded by the CARE Act, if available. Similarly, if a Medicaid recipient needs more home nursing visits then allowed by the state Medicaid program, programs funded by the CARE Act may pay for additional home nursing care.[5] The objective of this paper is to identify how the states provided medications and other treatments during 1995 with drug assistance programs (DAPs) funded by Tile II of the Ryan White CARE Act. The paper discusses characteristics of the DAPs established by the states, medical and financial eligibility criteria for DAPs, the use of any waiting lists for DAP benefits, and the coordination of Medicaid/DAP eligibility.

Methodology

To identify how the states are using Tile II funds to implement DAPs, state AIDS program directors were surveyed. The names and addresses of these directors in each state were obtained from the National Alliance of State and Territorial AIDS Directors.' In addition, the address file was updated with the names and addresses of AIDS program directors obtained from the Health Resources and Services Administration of the federal government.'

Survey Process

A DAP questionnaire was mailed to these AIDS program directors in May, 1995. Three additional mailings of the questionnaires were sent to the states not participating in the survey. When the survey was completed in early 1996, AIDS program directors (or their staffs) in 49 states and the District of Columbia provided DAP data (no reply was received from Rhode Island). The survey responses were summarized into tables and mailed to the AIDS program directors for verification and updates in April, 1996.

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Any additional information received during the verification process were added to the final tables used in this paper.

Incidence of AIDS

The incidence of AIDS and HIV infection varies widely among the states. Since the focus of this paper is the implementation of **DAPs** funded by Tile II during 1995, state-level AIDS rates per 100,000 population for **1995** were used to put state-level policies for **DAPs** into the context of the incidence of AIDS. The map for male adults/adolescent AIDS annual rates was used for this study to present the incidence of AIDS throughout the United States, with each state assigned to one of our four AIDS-incidence categories.' To illustrate the incidence of AIDS throughout the United States, the states were classified according to reported cases: highest incidence of AIDS (75 or more AIDS cases per 100,000 population); high incidence (50 to 74.9 AIDS cases per 100,000 population); medium incidence (25 to 49.9 AIDS cases per 100,000 population) or low incidence (0 to 24.9 AIDS cases per 100,000 population). Table **3-1** summarizes the categorization of the states by the incidence of AIDS.

Background

Drug therapies for the treatment of HIV infection and related opportunistic infections have emerged as the major method for improving the quality of life and increasing the length of survival for people with AIDS. Due to the large number of HIV-related opportunistic infections, the number of drug therapies **people** with AIDS and HIV infection require can be extensive. Nucleoside antiretroviral agents (e.g., zidovudine) delay the progression of HIV infection to AIDS.' Therapy with HIV **protease** inhibitors (e.g., saquinavir) has been shown to decrease viral loads and elevate CD4 cell counts with relatively few adverse effects." [11] Furthermore, the

Table 3-l:
Categorization of the States by AIDS Incidence Rates for Males (1995)

LOW INCIDENCE (Less than 25.0 cases per 109,000 population): Alaska, Arkansas, Idaho, Iowa, Indiana, Kentucky, Maine, Minnesota, Montana,Nebraska, New Hampshire, New Mexico, North Dakota, Ohio, Oklahoma, South Dakota, Utah, Vermont, West Virginia, Wisconsin, and Wyoming.

MEDIUM INCIDENCE (25 - 49.9 cases per 100,090 population): Alabama, Arizona, Colorado, Illinois, Kansas, Massachusetts, Michigan, Mississippi, Missouri, North Carolina, Oregon, Pennsylvania, Rhode Island, Tennessee, Virginia, and Washington.

HIGH INCIDENCE (SO - 74.9 cases per 100,000 population): Georgia, Hawaii, Louisiana, Nevada, South Carolina, and Texas.

HIGHEST INCIDENCE (75 and over cases per 100,000 population): California, Connecticut, Delaware, District of Columbia, Florida, Maryland, New Jersey, and New York.

combination of nucleoside antiretrovirals with prctease inhibitors may hold the greatest potential for reducing plasma HIV and increasing CD4 cell counts as compared to drug monotherapy.[12] Various drug therapies are used to treat or prevent pneumocystis carinii pneumonia (PCP),[13] toxoplasmosis,[14] mycobacterium avium complex,[15] and CMV retinitis.[16] The incidence rates of a number of opportunistic infections among people with HIV disease have declined over the past five years and are being diagnosed at a later stage of HIV disease due to the effective use of antiviral drugs, targeted preventive therapy, and more comprehensive clinical management of the disease."

DAP Characteristics

Health insurance coverage affects the access that people with HIV infection have to drug therapies. For example, a study of men with HIV infection, but without clinical AIDS, who lacked health insurance were less likely to receive antiretroviral therapy than similar men with health insurance." The same study concluded that people with AIDS covered by health insurance were more likely to receive antiretroviral therapy than the uninsured people with AIDS. Given the importance of drug therapies to the health status of people with HIV infection, and the association of health insurance with the use of these therapies, the DAPs funded by Tile II of the CARE Act are important components of the public sector safety net for HIV-related care. These DAPs not only can provide drug therapies to people with HIV who lack health coverage, but can benefit people with health insurance whose coverage does not include prescription drugs or Medicaid recipients who have exceeded the drug utilization limits many states impose.[19]

DAP Formulary

A formulary is a list of selected pharmaceuticals and their appropriate dosages that an insurer or program will cover or provide to people eligible for their services." In the context of this paper, a formulary refers to a listing of medications that the Title II-funded DAP in each state provide to eligible people. The questionnaire asked the AIDS program directors if the DAP in their state utilized a drug formulary, and if yes, the number of drugs on the formulary during 1995. As Table 3-2 illustrates, almost all DAPs funded by Tile II had drug formularies during 1995, with the number of drugs covered as high as 191 in New York.

The questionnaire asked how new drugs were added to the formulary during 1995. As Table 3-2 presents, the decision to add new drugs to the DAP formulary in most states is made by a board, panel, or committee. A number of states noted that the cost of medications or the availability of funds is part of the decision-making process when deciding to add new drugs to the formulary. The questionnaire asked the AIDS program directors to compare the number of drugs on the formulary in 1995 to the 1993 formulary. As Table 3-2 illustrates, the number of medications on DAP formularies during 1995 has increased since 1993 in most states. The questionnaire also asked the AIDS program directors if they expected the number of drugs on the DAP formulary in their state during 1996 to change when compared to 1995. As Table 3-2 documents, the number of drugs on DAP formularies during 1996 was expected to decrease in a number of states when compared to the number of drugs covered in 1995.

Table 3-2
Drug Assistance Programs Funded by Title II of the Ryan White CARE Act during 1995:
Prescription Drug Formularies

	Does DAP Have a 1995 Drug Formulary?	During 1995 the Number of Drugs on the Formulary was:	How are New Drugs Added to the Formulary?	Compared to 1993, the Number of Drugs on the 1995 Formulary has:	During 1996 the Number of Drugs on the Formulary is Expected to:	During 1995 Does the DAP Allow the Off-Label Use of Drugs on the Formulary?
Alabama	yes	7	Due to budget constraints, no new drugs are added	increased since 1993	increase in 1996	no
Alaska	no	not applicable	all up to the physician	no formulary	no formulary	yes - up to the physician
Arizona	yes	12	Recommendation by Ryan White advisory committee	increased since 1993	change - add and delete some drugs	yes
Arkansas	yes	8 ("Other drugs may be provided for a limited time.")	Each consortium may add to formulary according to their ability to pay.	increased since 1993	increase in 1996	no
California(1)	yes	43	edical Advisory recommend additions, if funds sufficient	increased since 1993	increase in 1996	not officially
Colorado	yes	14	added by a board/review committee decision	increased since 1993	decrease in 1996/ remain the same	yes
Connecticut(1)	yes	58	Meeting of Ct. AIDS Drug Advisory Committee	increased since 1993	increase in 1996	no
Delaware(1)	yes	30	apply to the formulary committee	increased since 1993	increase in 1996	no
District of Columbia(1)	yes	33	*	increased since 1993	increase in 1996	yes
	*The HADAP drug review and recommendation sub-committee reviews and accepts the drug for listing, which then requires a vote and quorum of the HADAP committee of the whole; the recommendation is processed through government channels and publicized in the District register.					
Florida(1)	yes	9	**	increased since 1993	increase in 1996	no
	**1. Antivirals receive priority; 2. drugs for prophylaxis and treatment of opportunistic infections based on rate of incidence and field recommendations; 3. statewide clinical formulary committee must approve recommendations.					
Georgia	yes	5	recommendation of statewide medical providers task force	increased since 1993	remain the same	no
Hawaii	yes	25	***	increased since 1993	increase in 1996	no
	***Request from physicians and the community, advice from medical advisor, availability of funds.					
Idaho	yes	8	~	increased since 1993	increase in 1996	yes
	~Providers and clients are surveyed about feasibility and need. Cost estimates are determined and STD/AIDS staff decide.					
Illinois	yes	110	~~	increased since 1993	decrease in 1996	yes - "We do not ask o monitor off-label use."
	~~"The Title II Advisory Committee makes recommendations to the Department. If the Department determines that it is feasible to add a new drug, administrative rules must be promulgated."					
Indiana	yes	20	recommendations made by advisory committee	increased since 1993	decrease in 1996	no - "We do not monitor this."
Iowa	no	not applicable	varies with each consortia	remain the same	increase in 1996	no
Kansas	yes	22	~~~	increased since 1993	increase in 1996	yes
	~~"A committee of the statewide consortium forwards a recommendation to the consortium for approval."					
Kentucky	yes	16	recommendations made by advisory panel	increased since 1993	remain the same (may decrease)	no answer
Louisiana	yes	>50				
	(no DAP - "Drugs are covered through charity hospitals and emergency assistance via [Title II] consortia.")					
Maine	yes	6	^	decreased since 1993	increase in 1996	no
	^A recommendation is made by an advisory subcommittee to the program's management and subsequent department approval.					
Maryland(1)	yes	25	MADAP Advisory Board determines additions	increased since 1993	increase in 1996	yes
Massachusetts	yes	not available	medical advisory board meets twice a year	increased since 1993	increase in 1996	no
Michigan	yes	15	recommendations from physician advisory group	increased since 1993	depends on FDA approval of drugs and funding	no
Minnesota	yes	34	^^	no formulary at first	increase in 1996	yes
	^^Reviewed by AIDS Physician Advisory Committee and approved by HIV/AIDS Programs Coordinator.					
Mississippi	yes	11	vote by Early Interv. and Care Committee for STD/HIV	increased since 1993	increase in 1996	no
Missouri	open formulary^^^	not applicable	FDA approved	increased since 1993	remain the same	yes
	^^^In addition, each Title II consortia in Missouri can elect to establish their own formulary. Effective 10/1/96 the Title II DAP in Missouri will establish a statewide formulary.					

Table 3-2
Drug Assistance Programs Funded by Title II of the Ryan White CARE Act during 1995:
Prescription Drug Formularies

	Does DAP Have a 1995 Drug Formulary?	During 1995 the Number of Drugs on the Formulary was:	How are New Drugs Added to the Formulary?	Compared to 1993, the Number of Drugs on the 1995 Formulary has:	During 1996 the Number of Drugs on the Formulary is Expected to:	During 1995 Doe5 the DAP Allow the Off-Label Use of Drugs on the Formulary?
Montana	yes	5	plan to establish a review panel	increased since 1993	remain the same	no
Nebraska	yes	23 (includes listing "antidepressant")	reviewed quarterly by Drug Util. Review Committee	remain the same	increase in 1996	no
Nevada	yes	not available	demand as noted by clinic/ physician/client requests	increased since 1993	increase in 1996	yes
New Hampshire	yes	not available	medical advisory board approves additions/deletions and restrictions	increased since 1993	remain the same	yes
New Jersey(1)	yes	44	#	increased since 1993	increase in 1996	yes
	#An FDA-approved drug is recommended by the Dept. of Health's AIDS Division. Approval is "based on survey results, a clinical review committee's recommendations and available funds?					
New Mexico	yes	33 (35 with multivitamins; in addition, contracep-tives are covered)	HIV/AIDS medical doctor and key Public Health personnel	increased since 1993	increase in 1996	no
New York(1)	yes	191	##	increased since 1993	decrease in 1996	yes
	##Recommended by a clinical subcommittee comprised of physicians with HIV specialization, pharmacists, nurses and people with HIV/AID					
North Carolina	ADAP funded with state money - no Title II funds.					
North Dakota	yes	45 (other drugs considered on an individual basis)	requested drugs checked for application to HIV/AIDS	increased since 1993	increase in 1996	no policy
Ohio	yes	12	drug advisory board meets semi-annually	increased since 1993	may increase in 1996	no
Oklahoma	yes	12	medical advisory committee decides	increased since 1993	remain the same	no answer
Oregon	yes	6	undefined process involving community, clients, doctors	increased since 1993	increase in 1996	if provider prescribes it, "we'll supply it."
Pennsylvania	Not applicable - Pennsylvania uses no Title II funds to support the statewide ADAP program.					
Rhode Island	no response to the survey					
South Carolina	yes	9	###	increased since 1993	"We hope to add treatments"	no policy
	### Doctors, nurses, patients, and case managers are surveyed. Drugs added based on financial feasibility.					
South Dakota	yes	33	@	increased since 1993	increase in 1996	yes
	@Ryan White administrator may add anytime or at the yearly advisory council meeting.					
Tennessee	yes	14	"Joint approval by the AIDS Program Director, a department medical advisor, and the HDAP Director."	increased since 1993	increase in 1996	yes
Texas	yes	22	!	increased since 1993	increase in 1996	yes
	! 1.request from public or medical community; 2. recommendation of advisory committee; 3. approval by Board of Health					
Utah	yes	"antivirals"	availability of funds and consensus with HIV/AIDS providers	decreased since 1993	remain the same	no
Vermont	no	not applicable	will fund any AIDS drug unless cost is prohibitive	not applicable	development of formulary in 1996	yes
Virginia	yes	11	"Professional consulta-tions and requests from practitioners."	increased since 1993	increase in 1996	no
Washington	yes	58	steering committee reviews & recommends changes	increased since 1993	increase in 1996	no
West Virginia	yes	6	reviewed by AIDS Program Budget & Request	increased since 1993	increase in 1996	no
Wisconsin	yes	10	"As directed by statute, outside experts must first be consulted."	increased since 1993	increase in 1996	no
Wyoming	no	not applicable	Drug must be approved by the FDA	remain the same	remain the same	yes

(1) States with the highest incidence of AIDS.

Source: Robert J. Buchanan, Ph.D., Department of Community Health, University of Illinois, a 1995 survey of state program administrators, Tii II of the Ryan White CARE Act. This research was funded by a grant from the Health Care Financing Administration, U.S. Department of Health and Human Services (grant # 18-P-90286/5-01).

Off-Label Use

Prior to marketing, a drug must be approved by the Food and Drug Administration (FDA) as safe and effective for uses described in a New Drug Application.*' Evidence of safety and efficacy are provided by the manufacturer from investigations of the drug's effects on controlled patient populations. These investigations substantiate the use of a drug for specific indications. Although a drug may have multiple uses, the FDA only approves labeling which reflects indications for conditions that have been researched within these trials. If later indications are studied, the drug manufacturer must file a supplemental application to the FDA in order to add a new indication to the labeling."

A physician, however, can prescribe a drug approved by the FDA for other indications besides those listed in the product label. In many circumstances the standard of care for a particular condition may include a drug not labeled for that use.[23] Prescribing a drug in this manner is commonly called "off-label" or "unlabeled use" and this practice is supported by such organizations as the FDA, the American Medical Association, and the American Society of Hospital Pharmacists.[24 25] In a study of oncologists, one-third of drug administrations were given for off-label uses? The absence of an indication within the product labeling, however, does not suggest that off-label use is experimental or inappropriate. In many cases there is considerable evidence in the medical literature to support an unlabeled indication. Instead, an omitted indication is typically one that has not been extensively studied by the drug manufacturer. Nevertheless, other researchers may have examined additional uses of the drug and reported their findings to the scientific community.

Many drugs used in the management of HIV or in the treatment of associated opportunistic infections are prescribed "off-label? Drugs like trimethoprim-sulfamethoxazole and clindamycin were developed years before the identification of HIV. Consequently, there is usually little incentive for drug manufacturers to expend resources to investigate new indications for drugs already marketed. Other uses for drugs like acyclovir and ciprofloxacin are well described in the medical literature; therefore a pharmaceutical company is likely to achieve better returns on investments made in other research than to investigate new indications for existing drugs. Even drugs like ganciclovir which was developed and is labeled for treatment of cytomegalovirus (CMV) retinitis in immunocompromised patients, also has unlabeled uses for other AIDS-related conditions?

Recent FDA actions increase the importance of allowing off-label uses of drugs in AIDS-related care. In response to the spread of HIV infection, the FDA has modified its policies to accelerate approval of drugs for serious and life threatening conditions, such as AIDS, and to allow access earlier in the approval process than previously permitted.[29 30] While these modifications have expanded the number of therapeutic agents available to treat HIV-related conditions, the labeling of many of these drugs has been approved with narrow indications which can constrain access for patients to these drugs if DAPs funded by Title II of the Ryan White CARE Act do not allow off-label use. Another reason for off-label use is that clinical expertise in the rapidly evolving field of AIDS-related care outdistances the regulatory process for approving new uses of drug therapies. As a result, policies preventing the unlabeled use of medications are particularly inequitable for drugs to treat AIDS-related conditions.

The questionnaire asked the AIDS program directors if the DAP in their state allowed the off-label use of drugs on the formulary during 1995. As Table 3-2 illustrates, Tile II-funded DAPs in a number of states allow off-label use, with some states noting that they do not monitor for this use. A policy permitting off-label use of medications allows the patients' physicians to prescribe the most appropriate drugs for treatment.

DAP Beneficiaries and Eligibility Policies

The CARE Act did not establish income restrictions for individuals to receive benefits from Tile II programs, although the statute did specify that CARE Act programs must be the payer of last resort.[31] Given the absence of federally-set income standards for eligibility, the states have the ability to establish their own financial eligibly criteria for individuals to receive Title II benefits. The survey asked the AIDS program directors to provide: the number of people receiving DAP benefits; medical and financial eligibility criteria for DAPs; spend down procedures for eligibility; and any use of waiting lists.

People Receiving HIV DAP Benefits

The questionnaire asked the AIDS program directors to estimate at the time of the survey (mid 1935) the number of people receiving benefits from the DAP funded by Tile II in their state, with these estimates presented in Table 3-3. The questionnaire also asked the AIDS program directors to estimate how the number of people receiving DAP benefits in 1995 compared to the number of people receiving these benefits in 1994. As Table 3-3 illustrates, most states reported that the number of DAP beneficiaries increased during 1995. In addition, the questionnaire asked the AIDS program directors to estimate how the number of people receiving DAP benefits in

Table 3-3
Drug Assistance Programs Funded by Tiie II of the Ryan White CARE Act during 1995:
Beneficiaries and ❑ igibility Criteria

	Estimates of the Number of People Receiving Prescription Drug Benefits from the Drug Assistance Program (DAP):			Medical Eligibility Requirements for DAP	To be Financially Eligible for DAP Gross Monthly Income during 1995 Cannot Exceed:	
	1995	1995 Compared to 1994	1996 Compared to 1995		1-Person Household	4-Person Household
Alabama	612	increase in 1995	increase in 1996	HIV+, CD4400	$1,867.50/month	$3,787.50/month
Alaska	6 to 8*	increase in 1995	increase in 1996 ("Changes to Medicaid would have big effect.")	HIV+, physician Rx for HIV-related condition, no other coverage	"not set - 'low income'"	"not set - 'low income'"
	("There's a Title IIIb-funded clinic in the area with most patients and it covers essentially all otherwise uncovered clients.					
Arizona	450	increase in 1995	increase in 1996	HIV+	$1,867/month	$3,787month
Arkansas	1000*	increase in 1995	increase in 1996	Drug program part of Consortia	$12,580/year	$25,520/year
California^	13,000 (estimate)	increase in 1995	increase in 1996	HIV+	$50,000/year	N/A
Colorado	700+	increase in 1995	increase in 1996	HIV+ and physician prescription	$1,085/month	$2,200/month
Connecticut^	670	increase in 1995	increase in 1996	HIV+, physician Rx for HIV-related condition, no other coverage	$1,868/month	$3,788/month
Delaware^	156	increase in 1995	remain the same	HIV+	$613.33/month	$2,281/month
District of Columbia^	600	increase in 1995	remain the same	HIV/AIDS diagnosis	$3,113/month	$6,313/month
Florida^	4,900	increase in 1995	increase in 1996	HIV+	$1,245/month	$2,526/month
Georgia	1,015	increase in 1995	increase in 1996	HIV+, CD4<500	125% of federal poverty level	125% of federal poverty level
Hawaii	135	remain the same	remain the same	HIV+, CD4<500	$2,151/month	$4,356/month
Idaho	40	remain the same	increase in 1996	HIV+, CD4<500	400% of poverty level	400% of poverty level
Illinois	1,500	increase in 1995	increase in 1996	diagnosed with HIV or AIDS	$2,490/month (4 times the federal poverty level)	$5,050/month
Indiana	505	increase in 1995	~	CD4<550	$1,868/month	$3,788/month
	~"There is now a waiting list, which will continue unless [Title II] is reauthorized and an increased award received."					
Iowa	132	increase in 1995	increase in 1996	HIV+	$1,246/month	$2,524/month
Kansas	300	increase in 1995	increase in 1996	HIV+	300% of poverty level	300% of poverty level
Kentucky	326	increase in 1995	increase in 1996	HIV+, CD4<550	$22,410/year	$45,450/year
Louisiana	(no DAP - "Drugs are covered through charity hospitals and emergency assistance via [Title II] consortia.")					
Maine	75	increase in 1995	increase in 1996	HIV+	$1,100/month	$2,300/month
Maryland^	308**	increase in 1995 (9-10%)	increase in 1996 (9-10%)	HIV+/AIDS**	$2,450/month	$3,367/month
Massachusetts	1,200	remain the same	increase in 1996	HIV+	$27,000/year	$37,000/year
Michigan	250	increase in 1995	unknown-depends on level of funding	not available	$2,299/month	$4,629/month
Minnesota	282~~	increase in 1995	increase in 1996	HIV+	$1,867.50/month	$3,787.50/month
	~~The actual number of people enrolled in the program was 345, but only 282 people actually used the benefit.					
Mississippi	835	increase in 1995	increase in 1996	varies with drug covered by DAP	$1,245/month	$2,525/month
Missouri	905	increase in 1995	increase in 1996	HIV+	$2,500/month	$5,000/month
Montana	20	remain the same	remain the same	no answer	$623/month (for full coverage)	$1,263/month (for full coverage)

Table 3-3
Drug Assistance Programs Funded by Title II of the Ryan White CARE Act during 1995:
Beneficiaries and Eligibility Criteria

	Estimates of the Number of People Receiving Prescription Drug Benefits from the Drug Assistance Program (DAP):			Medical Eligibility Requirements for DAP	To be Financially Eligible for DAP Gross Monthly Income during 1995 Cannot Exceed:	
	1995	1995 Compared to 1994	1996 Compared to 1995		1-Person Household	4-Person Household
Nebraska	178	increase in 1995	increase in 1996	HIV+	$1,245/month	$15,480/year
Nevada	560	increase in 1995	increase in 1996	HIV+, CD4<500, or HIV-linked illness without CD4 requirements	$1,896/month	$3,876/month
New Hampshire	68 (4/1-6/30/96	remain the same	increase in 1996	no answer	$22,410/year (300% of federal poverty level)	$45.450/year
New Jersey^	1,600	increase in 1995	increase in 1996	HIV+, physician certification	$2,500/month	$5,000/month
New Mexico	350	increase in 1995	increase in 1996	no answer	$1,869/month	$1,869/month
New York^	17,139~~~	increase in 1995	increase in 1996	HIV+	$3,666/month	$6,200/month
	~~17,139 people enrolled, with 10,686 people receiving one or more prescriptions in 1995					
North Carolina	ADAP funded with state money - no Title II funds.					
North Dakota	12	increase in 1995	increase in 1996	HIV+	no limit, however, "income level determines percentage paid but all are eligible for at least 80%."	
Ohio	600	increase in 1995	increase in 1996	HIV+	$1,374/month	$3,435/month
Oklahoma	250	increase in 1995	increase in 1996	no answer	$934/month	$1,894/month
Oregon	267	decrease in 1995	increase in 1996	HIV+, physician cert., CD4<500	"Gross [income] up to 274% federal poverty level, sliding scale if higher."	
Pennsylvania	Not applicable - Pennsylvania uses no Title II funds to support the statewide ADAP program.					
Rhode Island	no response to the survey					
South Carolina	406	increase in 1995	increase in 1996	HIV+, CD4<500	$1,867.50/month	$3,787.50/month
South Dakota	35	increase in 1995	increase in 1996	HIV+	$1,867.50/month	$3,787.50/month
Tennessee	250	increase in 1995	increase in 1996	HIV+	$1,868/month (net income)	$3,788/month (net income)
Texas	5,000	increase in 1995	increase in 1996	drug specific	$14,940/year	$31,420/year
Utah	185	increase in 1995	remain the same	HIV+ and ineligible for Medicaid	$623/month (sliding fee scale)	$1,263/month (sliding fee scale)
Vermont	55	increase in 1995	increase in 1996	HIV+	300% of poverty level, with adjust. for drug costs	300% of poverty level, with adjust. for drug costs
Virginia	1,000	increase in 1995	increase in 1996	HIV+	$1,245/month	$2,525/month
Washington	428	increase in 1995	increase in 1996	HIV+	$2,305/month	$4,673/month
West Virginia	43	remain the same	increase in 1996	HIV+	$1,569/month	$3,174/month
Wisconsin	350	increase in 1995	increase in 1996	HIV+	$1,290/month	$2,600/month
Wyoming	67	increase in 1995	increase in 1996	HIV+	$20,430/year	$41,850/year

^States with the highest incidence of AIDS.

*In Alaska and Arkansas prescription drugs are provided through the Title II Consortia program not a separate Title II DAP.

**In Maryland 308 people are enrolled in the DAP, with 166 people receiving benefits. To be eligible for DAP in Maryland the applicant "must submit written certification by a physician that the applicant has been diagnosed as having HIV infection or AIDS; meets other specific criteria established by the FDA or guidelines issued by the Secretary of the [Maryland] Dept. of Health and Mental Hygiene for receipt of drugs covered by MADAP and that the applicant will be treated with one or more drugs covered by MADAP."

Source: Robert J. Buchanan, Ph.D., Department of Community Health, University of Illinois, a 1995 survey of state program administrators, Title II of the Ryan White CARE Act. This research was funded by a grant from the Health Care Financing Administration, U.S. Department of Health and Human Services (grant # 18-P-90286/5-01).

1995 compared to the number of people expected to receive these benefits during 1996. Again, most AIDS program directors reported that the number of beneficiaries expected to receive DAP benefits will increase in 1996. (See Table 3-3.)

Medical Eligibility Requirements

The questionnaire asked the AIDS program directors to provide medical eligibility requirements for people to receive benefits from the DAP funded by Tile II during 1995. As the Table 3-3 demonstrates, most states responded that the individual must be HIV positive to meet medical eligibilii requirements and a number of states also linked eligibility to a maximum CD4 count. Mississippi and Texas noted that medical eligibility requirements varied with the drug covered by the DAP in that state. In Mississippi, for example, to receive Pentamidine a patient must have a CD4 count of 200 or less or have a documented episode of pneumocystis carinii pneumonia; Gancyclovir is maintenance therapy for patients with defined cytomegalovirus retinitis. In Texas, for example, to receive Acyclovir a patient must be diagnosed with HIV infection and acute or chronic **herpetic** infections; to receive **Itraconazole** a patient must be diagnosed with HIV infection and diagnosed histoplasmosis or blastomycosis; and to receive **Clarithromycin/Ethambutol** a patient must be diagnosed with HIV and current or previous diagnosis of mycobacterium avium complex.

Income Eligibility Requirements

The questionnaire asked the AIDS program directors to provide the maximum monthly income level an individual in a one-person household could have during 1995 to be eligible for the DAP funded by **Title** II. In addition, the AIDS program directors were asked to provide the maximum monthly income a family of four could have

during 1995 for an individual within that family to be eligible for the DAP. These financial eligibility requirements repotted by the states are presented in Table 3-3.

As Table 3-3 illustrates, the income ceilings established for DAP eligibility are relatively generous. This is particularly noticeable if these income eligibility standards for DAPs funded by Title II are compared to income eligibility standards for state Medicaid coverage (the largest payer of AIDS-related care.) For example, during 1993 most individuals with AIDS could not have incomes in excess of $434 per month to receive Medicaid coverage in most states? Hence, DAPs funded by Title II can provide services to people infected with HIV who have incomes too high to become eligible for Medicaid coverage, strengthening the public-sector safety net for funding the care needed by people with HIV-related illness.

Trends in Financial Eligibility

The questionnaire asked if financial eligibility criteria for services provided by DAPs during 1995 have become more restrictive since 1993, providing responses of "more restrictive in 1995," less restrictive in 1995," or "remain the same." While financial eligibilii for DAPs funded by Title II remained the same in most states, these criteria have changed in many states as Table 3-4 illustrates. The questionnaire also asked the AIDS program directors if they expected financial eligibility criteria for DAPs to become more restrictive during 1996. The AIDS program directors in most states reported that financial eligibility criteria are expected to remain the same during 1996, as Table 3-4 presents.

Table 3-4

Dtug Assistance Programs Funded by Tii II of the Ryan White CARE Act during 1995: Trends in Financial Eligibility and Waiting Lists for Eligibility

	Compared to 1993, Financial Eligibility Criteria for DAP in 1995 have Become:	During 1996 Financial Eligibility Criteria for DAP is Expected to Become:	Do DAP Eligibility Determination Procedures Include Spend Down?	Is There a Waiting List of People for DAP Eligibility During 1995?	If There is a DAP Waiting List, Estimate the Following for 1995:	
					Number of People on the Waiting List	Length of Time on the Waiting Li
Alabama	remained the same	remain the same	no	yes	100 people	60 days
Alaska	more restrictive in 1995	remain the same	no	no*	not applicable	not applicable
				*There are "people who cannot get meds covered due to lack of [Title II] funds."		
Arizona	less restrictive in 1995	remain the same	no	no	not applicable	not applicable
Arkansas	remained the same	remain the same	yes	yes	not available	not available
California^	remained the same	remain the same	no	no	not applicable	not applicable
Colorado	less restrictive in 1995	remain the same	yes	no	not applicable	not applicable
Connecticut^	less restrictive in 1995	remain the same	yes	no	not applicable	not applicable
Delaware^	more restrictive in 1995	remain the same	no	yes	5 people	100 days
District of Columbia^	remained the same	remain the same	yes	no	not applicable	not applicable
Florida^	remained the same	remain the same	no	no	not applicable	not applicable
Georgia	remained the same	remain the same	no	no	not applicable	not applicable
Hawaii	remained the same	remain the same	no	no	not applicable	notappliі
Idaho	remained the same	remain the same	no	no	not applicable	not applicable
Illinois	less restrictive in 1995	more restrictive in 1996	no	no	not applicable	not applicable
Indiana	remained the same	remain the same	no	yes. beginning 12/1/95	approximately 15 in 12/95	open-ended
Iowa	remained the same	remain the same	no	no	not applicable	not applicable
Kansas	remained the same	remain the same	no	no	not applicable	not applicable
Kentucky	less restrictive in 1995	remain the same	no	no	not applicable	not applicable
Louisiana	(no DAP - "Drugs are covered through charity hospitals and emergency assistance via [Title II] consortia.")					
Maine	less restrictive in 1995	less restrictive in 1996	no	no	not applicable	not applicable
Maryland^	less restrictive in 1995	remain the same	no	no	not applicable	not applicable
Massachusetts	less restrictive in 1995	remain the same	no	no	not applicable	not applicable
Michigan	more restrictive in 1995	unknown - depends on funding level	no	no	not applicable	not applicable
Minnesota	remained the same	remain the same	yes	no	not applicable	not applicable
Mississippi	remained the same	remain the same	no	no	not applicable	not applicable
Missouri	less restrictive in 1995	more restrictive in 1996	no	no	not applicable	not applicable
Montana	remained the same	remain the same	no	no	not applicable	not applicable
Nebraska	remained the same	more restrictive in 1996	yes	no	not applicable	not applicable

Table 3-4
Drug Assistance Programs Funded by Tii II of the Ryan White CARE Act during 1995:
Trends in Financial Eliiibilii and Waiting Lists for Eliiibilii

	Compared to 1993, Financial Eligibility Criteria for DAP in 1995 have Become:	During 1996 Financial Eligibility Criteria for DAP is Expected to Become:	Do DAP Eligibility Determination Procedures Include Spend Down?	Is There a Waiting List of People for DAP Eligibility During 1995?	If There is a DAP Waiting List, Estimate the Following for 1995:	
					Number of People on the Waiting List	Length of Time on the Waiting List
Nevada	remained the same	remain the same	yes	yes**	0	0
				**"Technically, we do have the mechanics for a waiting list."		
New Hampshire	remained the same	remain the same	yes	no	not applicable	not applicable
New Jersey^	remained the same	remain the same	no	no	not applicable	not applicable
New Mexico	more restrictive in 1995	more restrictive in 1996	no	no	not applicable	not applicable
New York^	remained the same	remain the same	no	no	not applicable	not applicable
North Carolina	ADAP funded with state money - no Title II funds.					
North Dakota	less restrictive in 1995	remain the same	no	no	not applicable	not applicable
Ohio	remained the same	remain the same	yes	no	not applicable	not applicable
Oklahoma	more restrictive in 1995	remain the same	yes	no ("But we are anticipating one."	not applicable	not applicable
Oregon	remained the same	remainthesame	no	no	notappliible	not appkabie
Pennsylvania	Not applicable - Pennsylvania uses no Tii II funds to support the statewide ADAP program.					
Rhode Island	no response to the survey					
South Carolina	"Based on poverty levels, adjusted yearly."		no	yes	200	6-8 months
South Dakota	remainedthesame	remain the same	no	no	not applicable	not applicable
Tennessee	less restrictive in 1995	remaintheeame	no	no	notappliible	not applicable
Texas	remained the same	remain the same	yes - but cost of medications only	no	not applicable	not applicable
Utah	remained the same	remain the same	no	no	not applicable	not applicable
Vermont	remained the same	remainthesame	yes	no	not applicable	not applicable
Virginia	remainedthesame	remainthesame	yes	no	0	not applicable
Washington	remained the same	remainthesame	no	no	not applicable	not applicable
West Virginia	remained the same	remainthesame	no	no	not applicable	notapplicable
W i n	more restrictive in 1995	remain the same	no	no	not applicable	not appliible
Wyoming	remained the same	more restrictive in 1996	no	no	not appliible	not applicable

^States with the highest incidence of AIDS.

Source: Robert J. Buchanan. Ph.D., Department of Community Health, University of Illinois, a 1995 survey of state program administrators, Tii II of the Ryan White CARE Act. This research was funded by a grant from the Health Care Financing Administration, U.S. Department of Health and Human Services (grant #18-P-90286/5-01).

Spend Down Procedures

The questionnaire asked the AIDS program directors if eligibility determination procedures for DAPs funded by Tile II include a spend down provision. Spend down was defined on the questionnaire as "allowing the applicant to deduct the cost of medical care from income levels and using this medical-cost adjusted income level for eligibility determination." (Most state Medicaid programs allow spend down when determining Medicaid eligibility.[33]) As Table 3-4 documents, most states do not include spend down provisions in the determination of financial eligibility for DAPs funded by Tile II.

Waiting Lists

The questionnaire asked if there was a waiting list of people in their state waiting to receive benefits from DAPs funded by Title II during 1995. If there was a waiting list, the AIDS program directors were asked to estimate both the number of people currently on the waiting list at the time of the survey and the number of days a person had to wait to receive benefits during 1995. Based on the survey responses, Alabama, Arkansas, Delaware, Indiana, and South Carolina reported that there were people waiting to receive DAP coverage, with the wait as long as six to eight months in South Carolina. In addition, Alaska noted that in that state there are "people who cannot get [medications] covered due to the lack of [Title II] funds." Oklahoma anticipates implementing a waiting list in the future. Nevada reported that the DAP in that state has the mechanics in place for a waiting list, although no one was waiting for DAP coverage at the time of the survey.

Coordination with Medicaid

Although the CARE Act specifies that Tile II funds must be the payer of last resort, Title II programs can supplement Medicaid coverage if Medicaid does not cover a needed health service or if a recipient's care needs exceed Medicaid utilization limits. The state Medicaid programs and Tile II programs can coordinate services to provide a continuum of care and eliminate duplication of services, serving the care needs of people with HIV diseases more efficiently? [35] State Tile II programs also can access Medicaid eligibility information, allowing them to determine if Title II beneficiaries are also eligible to receive Medicaid coverage? If Title II recipients are determined to be Medicaid eligible, CARE Act resources can then be used to provide medications to other low income people with HIV or AIDS?

Title II/Medicaid Utilization Limits

The questionnaire asked the AIDS program directors if the Medicaid program in their state "limits utilization of the prescription drug benefit (e.g., 5 prescriptions per month), does the HIV/AIDS DAP funded by Title II in your state cover the prescription drug use in excess of the Medicaid limits?" To facilitate responses, the questionnaire provide "yes," "no," and "no Medicaid drug utilization limits" as possible responses. As Table 3-5 documents, the DAP funded by Title II in many states did not cover needed prescriptions in excess of Medicaid utilization limits. The DAP in South Carolina did assist Medicaid patients with AIDS/HIV obtain medications after they exhausted their Medicaid benefit of three prescriptions per month, but the DAP had to "suspend this policy due to lack of funds."

Table 3-5
Drug Assistance Programs Funded by Title II of the Ryan White CARE Act during 1995:
Coordination with the State Medicaid Program

	Is Eligibility for DAP Coordinated with Eligibility for the state Medicaid Program?	Does DAP Cover Drug Use in Excess of Any Medicaid Drug Limits?
Alabama	yes - a person receiving Medicaid coverage is ineligible for DAP	no
Alaska	yes - case managers assist people with Medicaid application; DAP does not cover anything Medicaid covers	no Medicaid drug utilization limits
Arizona	no	no Medicaid drug utilization limits
Arkansas	yes - "If the client is Medicaid eligible, the most expensive drugs (and there can only be 3) are placed on the Medicaid card. The consortia either pays [for other drugs] directly or finds additional funding sources."	yes
California^	"Yes, if a person is eligible for Medicaid, they are not eligible for ADAP."	yes
Colorado	"If a client has prescription coverage through Medicaid, he/she is not eligible for our drug assistance program."	no
Connecticut^	yes - only people not eligible for Medicaid or people waiting for Medicaid eligibility can be on DAP	no Medicaid drug utilization limits
Delaware^	yes - case managers work to assure that Medicaid-eligible clients are placed on Medicaid	no Medicaid drug utilization limits
District of Columbia^	yes - the DAP "will have an ACEDS terminal so that clients can be removed from [DAP] upon Medicaid determination. Also, in the past the Medicaid office has participated in the development of the [DAP] program."	no
Florida^	yes - a client that is eligible for Medicaid is not eligible for the DAP in Florida	no Medicaid drug utilization limits
Georgia	yes - "proof of documentation of income"	no
Hawaii	no	yes
Idaho	no	no
Illinois	yes - "Program applicants are assisted in applying for Medicaid benefits, if eligible. Program participants are monitored for enrollment in Medicaid."	no
Indiana	yes - "We verify/monitor Medicaid status monthly. If they are put on Medicaid, they are taken off ADAP."	no - "I don't know if there are limits, but we don't have people in both programs."
Iowa	no	no answer
Kansas	yes	yes
Kentucky	yes - if client is Medicaid eligible, he/she is not eligible for DAP.	no Medicaid drug utilization limits
Louisiana	no DAP - "Drugs are covered through charity hospitals and emergency assistance via [Title II] consortia."	"consortia might"
Maine	yes - the DAP in Maine accesses the Medicaid screen to determine eligibility and/or reimbursement	no
Maryland^	yes - "Applicant must indicate on application if he/she is not Medicaid eligible. Persons eligible for Medicaid are not eligible for MADAP."	no
Massachusetts	no	no Medicaid drug utilization limits
Michigan	yes	no
Minnesota	yes - "We screen applicants for Medicaid eligibility and refer there if appropriate. We have access to Medicaid eligibility files to verify [eligibility].	no Medicaid drug utilization limits
Mississippi	yes - covers prescription drugs in excess of Medicaid limit	yes
Missouri	yes - check Medicaid eligibility at time of enrollment	no Medicaid drug utilization limits

Table 3-5
Drug Assistance Programs Funded by Tii II of the Ryan White CARE Act during 1995:
Coordination with the State Mediiid Program

	Is Eligibility for DAP Coordinated with Eligibility for the state Medicaid Program?	Does DAP Cover Drug Use in Excess of Any Medicaid Drug Limits?
Montana	yes - "client may be accepted on a provisional basis, but must apply for and be declared ineligible for Medicaid within 90 days."	no answer
Nebraska	yes - all applicants checked for Medicaid enrollment at application	no Medicaid drug utilization limits
Nevada	yes - shared electronic verification with eligibility computer link.	no
New Hampshire	"HADAP eligibility is reviewed monthly along with Medicaid. eligibility. Medicaid eligibles are removed from HADAP eligibility."	no Medicaid drug utilization limits
New Jersey^	yes - DAP, Medicaid, and Pharmaceutical Assistance to Aged and Disabled applications screened by Medicaid	yes
New Mexico	no	no Medicaid drug utilization limits
New York^	yes - "All applicants are checked for Medicaid enrollment at application and periodically thereafter. Denied if Medicaid enrolled. Medii application encouraged. Program assists with meeting Medicaid spend down requirement."	no Medicaid drug utilization limits
North Carolina	"ADAP funded with state money - no Title II funds."	"ADAP funded with state money - no Title II funds."
North Dakota	yes - Ryan White is payer of last resort.	yes
Ohio	yes - "We have clients on HADAP who are not yet Medicaid eligible.'	yes (but not sure)
Oklahoma	yes-"Casemanagerscoordinatethedrugsoffersdonths HADAP with ths 3 Rxs available through Medicaid."	Yes
Oregon	"Yes - ADAP is provider/payer of tast resort."	Yes
Pennsylvania	"Not applicable - Pennsylvania uses no Tii II funds to support the statewide ADAP program."	
Rhode Island	no response to ths survey	no
South Carolina	no	no
South Dakota	yes - "If people are eligible for Medicaid, Medicaid pays for their drugs."	no Medicaid drug utilization limits
Tennessee	yes - DAP will not cover what TennCare (Medicaid) covers	yes, but TennCare has no drug utilization limits
Texas	yes - DAP will cover medications in excess of the Medicaid limit	yes
Utah	yes	no Medicaid drug utilization limits
Vermont	no	no Medicaid drug utilization limits
Virginia	yes - "A person on the HADAP must be declared ineligible for Medicaid."	no
Washington	yes - DAP "assists clients in meeting their Medicaid spend down."	no Medicaid drug utilization limits
West Virginia	yes - "Person applies at Medicaid office and automatically is eligible when in Medicaid spend down."	no Medicaid drug utilization limits
Wisconsin	yes - "Computerized [Medicaid] client database is available in AIDS/HIV program to cross-check eligibility."	yes
Wyoming	yes - as soon as client is on Medicaid, Medicaid payments for prescription drugs begin.	yes

^States with the highest incidence of AIDS.

Source: Robert J. Buchanan, Ph.D., Department of Community Health, University of Illinois, a 1995 survey of state program administrators, Title II of the Ryan White CARE Act. This research was funded by a grant from the Health Care Financing Administration, U.S. Department of Health and Human Services (grant # 18-P-90286/5-01).

Title II /Medicaid Eligibility Coordination

The questionnaire asked the AIDS program directors if eligibility for the DAP is "coordinated with eligibility for Medicaid in your state?" As Table 3-5 indicates, DAP eligibility is coordinated with Medicaid eligibility in most states. Many states reported that this Medicaid/DAP eligibility coordination guarantees that Tiie II is the payer of last resort. The DAPs in a number of states noted that they cover prescription drug needs in excess of the Medicaid limits implemented in those states. The AIDS program directors in Washington State and West Virginia reported that the DAPs in these states assist clients who are in the process of spending down to Medicaid eligibility.

Summary and Discussion

Public programs, particularly the state Medicaid programs, pay for the health services provided to most people with AIDS and a significant percentage of people infected with HIV.[38] However, the Medicaid programs establish restrictive eligibility criteria, requiring during 1993 that incomes be below $434 per month in most states.[39] Programs funded by the Ryan White CARE Act provide services to people with AIDS and HIV infection with higher income levels, broadening and strengthening the public-sector safety net for financing HIV-related health care. This paper focused on the DAPs funded by Tile II of the CARE Act, presenting data on DAP characteristics, medical and financial eligibility criteria for DAPs, and coordination of DAP/Medicaid eligibility.

Most Tile II-funded DAPs had formularies, with the number of drugs included ranging as high as 191 medications in New York during 1995. The decision to add new drugs to the DAP formulary is made by a board, panel, or committee in most

states, with a number of states noting that the cost of medications or the availability of funds affects these decisions. Although it would allow health providers to prescribe the most appropriate drug therapies, the DAPs in some states do not allow the off-label use of medications.

The study also identified the medical and financial criteria necessary for individuals to become eligible for DAPs. The study documents that the state Title II programs have established generous income eligibility standards for services provided by DAPs, especially when compared to Medicaid eligibility standards. Hence, DAPs funded by Tile II can provide drug therapies to people infected with HIV who have incomes too high to become eligible for Medicaid coverage. The Title II programs strengthen the public-sector safety net for funding the care needed by people with HIV-related illness.

Many states coordinate Medicaid/DAP eligibility to guarantee that Title II is the payer of last resort, helping the DAPs to serve other low-income people with AIDS or HIV who lack other coverage. DAPs funded by Title II in a number of states cover the prescription drug needs of Medicaid recipients with HIV or AIDS in excess of the Medicaid limits implemented in these states. DAPs also can provide drug coverage to people with AIDS or HIV who are in the process of becoming eligible for Medicaid benefits.

Generous eligibility criteria and coverage of a broad array of medications by DAPs allow these Title II programs to strengthen the public-sector safety net for financing the care needed by people with HIV-related illness. DAPs funded by Title II provide needed medications to people with HIV disease before they become eligible for Medicaid or Medicare?' (However, since Medicare generally does not cover

outpatient prescription drugs, the DAPs will continue to be an important source of drug coverage for lower-income people with HIV receiving Medicare benefits.) Generous eligibilii criteria (or no income restrictions in some states), however, can become a double-edged sword. If federal funding for Title II programs is not sufficiently increased to keep up with the increasing number of people expected to receive benefits from Tile II programs, or if future federal Medicaid reform allows the states to establish even more restrictive Medicaid eligibility standards, then the Tile II programs may not be able to provide services for all eligible people. DAPs in a number of states reported the use of waiting lists. The DAP in South Carolina responded that due to the lack of funds it can no longer cover the drugs needed by Medicaid recipients with HIV or AIDS that exceed the drug utilization limits 'implemented by the Medicaid programs in that state. The DAP in Illinois reduced the number of covered drugs to 28 on July 1, 1996 because of the high costs of medications provided.[41] Given the encouraging results of the new protease inhibitors in treating HIV infection,[42] and the $12,000 to $15,000 annual cost of these and other drugs per person when used in a combination therapy or a 'three-drug cocktail",[43] the DAPs funded by Tie II will face increasing fiscal pressures. In fact, some states are already tightening eligibility, reducing the number of covered drugs, or implementing copayments.““ If federal funding for Tile II programs in the future does not keep pace with the expected increase in the number of people eligible for Tile II services, and the costs of services provided, then the public-sector safety net for financing HIV-related care will be weakened.

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Chapter 4
Home and Community-Based Care Funded by Title II of the Ryan White CARE Act[a]

Introduction

The Ryan White Comprehensive AIDS Resource Emergency (CARE) Act (Public Law 101-381) was enacted in August, 1990 to improve both the quality and availability of care for people with HIV disease and their families.' The original legislation authorized: grants to metropolitan areas with the largest number of AIDS cases to help provide emergency services (Title I); grants to the states to improve the quality, availability, and organization of health and related support services (Title II); grants to state health departments for AIDS early intervention services (Title Ill-a) and community-based primary care facilities (Title Ill-b); and grants for research and evaluation initiatives, including demonstration programs for pediatric AIDS research (Title IV).[2] Title II of the CARE Act allows states to allocate funds among any or all of four areas to: cover home-based health services, provide medication and other treatments, continue private health insurance coverage, or fund HIV care consortia.[3] The objective of this paper is to identify how the states are using Title II funds to implement home and community-based care programs. The paper identifies states that have implemented home and community-based care programs with Title II funds, the home and community-based services offered, medical and financial eligibility criteria, and coordination with the state Medicaid programs.

Methodology

To identify how the states are using Title II funds to implement home and community-based care programs, state AIDS program directors were surveyed. The

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names and addresses of these directors in each state were obtained from the National Alliance of State and Territorial AIDS Directors.[4] In addition, the address file was updated with the names and addresses of AIDS program directors obtained from the Health Resources and Services Administration of the federal government?

Survey Process

A home and. community-based care questionnaire was mailed to these AIDS program directors in May, 1995. Three additional mailings of the questionnaires were sent to the states not participating in the survey. When the survey was completed in early 1996, AIDS program directors (or their staffs) in 49 states and the District of Columbia provided data (no reply was received from Rhode Island). The survey responses were summarized into tables and mailed to the AIDS program directors for verification and updates in April, 1996. Updates and any additional information received during the verification process were added to the final tables used in this paper.

Incidence of AIDS

The incidence of AIDS and HIV infection varies widely among the states. Since the focus of this paper is the implementation of home and community-based care programs funded by Tile II during 1995, state-level AIDS rates per 100,000 population for 1995 were used to put state-level policies for home and community-based care programs into the context of the incidence of AIDS. The map for male adults/adolescent AIDS annual rates was used for this study to present the incidence of AIDS throughout the United States, with each state assigned to one of our four AIDS-incidence categories? To illustrate the incidence of AIDS throughout the United States, the states were classified according to reported cases: highest incidence of

Table 4-1:
Categorization of the States by AIDS Incidence Rates for Males (1995)

LOW INCIDENCE (Less than 25.0 cases per 100,000 population): Alaska, Arkansas, Idaho, Iowa, Indiana, Kentucky, Maine, Minnesota, Montana,Nebraska, New Hampshire, New Mexico, North Dakota, Ohio, Oklahoma, South Dakota, Utah, Vermont, West Virginia, Wisconsin, and Wyoming.

MEDIUM INCIDENCE (25 - 49.9 cases per 100,000 population): Alabama, Arizona, Colorado, Illinois, Kansas, Massachusetts, Michigan, Mississippi, Missouri, North Carolina, Oregon, Pennsylvania, Rhode Island, Tennessee, Virginia, and Washington.

HIGH INCIDENCE (50 - 74.9 cases per 100,000 population): Georgia, Hawaii, Louisiana, Nevada, South Carolina, and Texas.

HIGHEST INCIDENCE (75 and over cases per 100,000 population): California, Connecticut, Delaware, District of Columbia, Florida, Maryland, New Jersey, and New York.

AIDS (75 or more AIDS cases per 100,000 population); high incidence (50 to 74.9 AIDS cases per 100,000 population); medium incidence (25 to 49.9 AIDS cases per 100,000 population) or low incidence (0 to 24.9 AIDS cases per 100,000 population). Table 4-1 summarizes the categorization of the states by the incidence of AIDS.

Home and Community-Based Care Programs

Table 4-2 presents the states that did not implement home and community-based care programs with Title II funds during 1995. However, as Table 4-2 illustrates, HIV consortia funded by Tile II provided home and community-based services in many of these states. The states that reported implementing home and community-based care programs with Title II funds during 1995 are presented in Table 4-3.[7]

Home and Community-Based Services

The questionnaire asked the AIDS program directors to describe the services covered by the home and community-based care programs funded by Tile II during 1995. To facilitate responses, the questionnaire offered a listing of 15 home and community-based services along with a response of "other (please describe)," with a request to circle any that apply. The 15 home and community-based care listed on the questionnaire are:

durable medical equipment
home health services
day treatment and partial hospitalization
aerosolized drug therapy
dental services
mental health, development, and rehab services
transportation to health care
HIV prevention education for families
homemaker services
personal care services
home intravenous therapy
in-home diagnostic testing
home hospice care
case management
child care services
other (please describe):

Table 4-2
States Not Implementing Home and Community-Based Care Programs
Funded by Title II of the Ryan White CARE Act during 1995

	The Home and Community-Based Care Services Funded by Title II During 1995:
Alabama	The Tiie II program in Alabama did not have a Home and Community-Based Care Program in 1995. but the consortia program did cover home and community-based services.
Alaska	The Title II program in Alaska did not have a Home and Community-Based Dare Program in 1995 due to insufficient funds.
Arizona	The Tiie II program in Arizona did not have a Home and Communttv-Based Dare Program in 1995. but the consortia program did cover home and community-based services.
Arkansas	The Tiie ‖ program in Arkansas did not have a Home and Community-Based Dare Program in 1995.
Colorado	The Title ‖ program in Colorado did not have a Home and Community-Based Dare Program in 1995, but the consortia program did cover home and community-based services. 'Some [consortia] treat it like any any other Ryan White service area; others do not provide it at all.'
Connecticut^	The Tiie ‖ program in Connecticut covered many home and oommunity-based services through the Ryan White consortia program in 1995.
Florida^	The Title II program in Florida did not have a t-tome and Community-Based Dare Program in 1995. Other Title II programs, such as the consortia, covered home and community-based services in Florida based on an assessment of individual need. The Medicaid AIDS Waiver provides these services on a statewide basis.
Hawaii	The Tii ‖ program in Hawaii did not have a Horn: and Community-Based Dare Program in 1995.
Idaho	The Tiie ‖ program in Idaho did not have a Home and Community-Based Dare Program in 1995.
Illinois	The Title ‖ program in Illinois did not have a Home and Community-Based Dare Program in 1995, but local Title II consortia may provide home and community-based services.
Indiana	The Tiie II program in Indiana did not have a Home and Community-Based Dare Program in 1995.
bwa	The Title II program in bwa did not have a Home and Community-Based Dare Program in 1995.
Missouri	The Title II program in Missouri did not have a Home and Community-Based Dare Program in 1995.
Montana	The Title II program in Montana did not have a Home and Community-Based Dare Program in 1995.
Nebraska	The Title II program in Nebraska did not have a Home and Community-Based Dare Program in 1995. (However, similar services are available from the Nebraska Department of Social Services.)
North Carolina	Home and community-based services funded by Title II were provided through consortia in North Carolina during 1995 and may be provided on a state-level during 1996.
North Dakota	The Title ‖ program in North Dakota did not have a Home and Community-Based Dare Program in 1995.
Oregon	The Titie II program in Oregon did not have a Home and Community-Based Dare Program in 1995, but local Tiie II consortia provided home and community-based services.
Pennsylvania	Not applicable because Pennsyivania does not administer these programs directly with Title II funds. [Individual consortia may provide these services in Pennsylvania.]
Rhode Island	no response to the survey
South Carolina	The Title II program in South Carolina did not have a Home and Community-Based Dare Program in 1995, but local Title II consortia may provide home and community-based services as needed.
Texas	The Title II program in Texas did not have a separate Home and Community-Based Dare Program in 1995, but home and community-based services were combined with Tiie II HIV Dare Consortia.
Vermont	The Title II program in Vermont did not have a Home and Community-Based Care Program in 1995.
Virginia	The Tie II program in Virginia did not have a Home and Community-Based Dare Program in 1995. However, some consortia cover this care.
West Virginia	The Title II program in West Virginia did not have a Home and Community-Based Dare Program in 1995.
Wisconsin	The Title II program in Wisconsin did not have a Home and Community-Based Dare Program in 1995.

^States with the highest incidence of AIDS.

Source: Robert J. Buchanan, Ph.D., Department of Community Health, University of Illinois, a 1995 survey of state program administrators, Tiie II of the Ryan White CARE Act. This research was funded by a grant from the Health Dare Financing Administration, U.S. Department of Health and Human Services (grant #18-P-90286/5-01).

The services provided by the home and community-based care programs funded by Tile II in the states and the District of Columbia are summarized in Table 4-3. In addition to the home and community-based care services listed on the questionnaire, a number of states reported coverage of other services as well. Among these other home and community-based care services provided during 1995 were: food and housing assistance, ophthalmic services, psychosocial counseling, benefits counseling, nutritional counseling and supplements, home-delivered meals, RN visits and assessments, physical and occupational therapy, professional nursing services, day care, respite care, primary medical care, advocacy services, food banks, early intervention services, rural initiatives, spiritual counseling, and escort services for health care staff visiting clients in high crime areas.

Trends in Services Offered

The questionnaire asked the AIDS program directors to compare the number of services offered by the home and community-based care programs in their state during 1995 to the number of services covered in 1994. As Table 4-4 illustrates, about one half of the states with home and community-based care programs funded by Tile II reported that the number of services remained the same and the rest of the states reported the number of services increased in 1995, with no states reporting a decrease. The questionnaire also asked the AIDS program directors to estimate how the number of home and community-based care services expected to be offered in their state during 1996 compares to the number of services covered in 1995. As Table 4-4 presents, the AIDS program directors in most states reported that the number of services provided by Title II home and community-based care programs is expected to remain the same in 1996, with increases expected in a few states. The number of

Table 4-3

Home and Community-Based Care Programs Funded by Tii II of the Ryan White CARE Act during 1995: Home and Community-Based Services

	The Home and Community-Eased Care Services Funded by Tii II During 1995:
California^	durable medical equipment. home health services, mental health services, transportation to health care, HIV prevention education for families, homemaker services, personal care services, home intravenous therapy, in-home diagnostic testing, home hospice care, case management, food and housing assistance, psychosocial counseling, benefits counseling. nutritional counseling and supplements, and home-delivered meals
De&war&	durable medical equipment, home health services, day treatment and partial hospitalization, aerosolized drug therapy. dental services, mental health services. transportation to health care. ophthalmic services, homemaker services, personal care services, home intravenous therapy, and in-home diagnostic testing
District of Columbia^	durable medical equipment. home health services, homemaker services, personal care services, home intravenous therapy, physical and occupational therapy services, and professional nursing services
Georgia	case management
Kansas	durable medical equipment, home health services, day treatment and partial hospitalization, aerosolized drug therapy, homemaker services, personal care services, home intravenous therapy, in-home diagnostic testing, and home hospice care
Kentucky	durable medical equipment. home health services, dental services, mental health services, transportation to health care, HIV secondary prevention education for families, homemaker services, personal care services, home intravenous therapy, in-home diagnostic testing, home hospice care, case management, day/respite care, primary medical care, advocacy services, and food bank
Louisiana	durable medical equipment, home health services, aerosolized drug therapy, mental health services, personal care services, home intravenous therapy, in-home diagnostic testing, and home hospice care
	"Other services are funded with State money from the Department of Health and Hospitals."
Maine	home health services, aerosolized drug therapy, dental services, mental health services, transportation to health care, HIV prevention education for families. homemaker services, personal care services, home inbavenous therapy, in-home diagnostic testing, and case management
	"Under contract, Title II funds case management agencies statewide to provide linkage to many services covered under Home and Community Based Services.
Maryland^	durable medical equipment, home health services, aemsolii drug therapy. mental health services, transportation to health care, homemaker services, personal care services, home intravenous therapy, and home hospice care
Massachusetts	homemaker services
Michigan	durable medical equipment, home health services, dental services, mental health services, transportation to health care, homemaker services, personal care services, home intravenous therapy, in-home diinoslic testing. home hospice care, case management, child care, and secondary prevention services
	"These are not all considered eligible services through the HCBC program but are covered by some consortia through consortia activities."
Minnesota	dental services, mental health services, transportation to health care and social services, families, homemaker and personal care services (maintenance only). case management, early intervention, rural initiatives, complementary services, information and referral, emergency monetary assistance. and day care
Mississippi	aerosolized drug therapy and home intravenous therapy
Nevada	home health services, dental services, mental health services, transportation to health care, HIV prevention education for families, homemaker services. personal care services, home intravenous therapy, home hospice care. case management delivered meals, spiritual counseling, and housing assistance
New Hampshire	durable medical equipment. home health services, day treatment and partial hospitalization, aerosolized drug therapy, mental health, development, and rehab services, homemaker services, personal care services, home intravenous therapy, in-home diagnostic testing, and case management
New Jersey^	durable mediil equipment, day treatment services, aerosolized drug therapy, mental health services, homemaker services, personal care services, home inbavenous therapy, in-home diagnostic testing' case management and escort services for professional and paraprofessional staff visiting clients in high crime areas
New Mexico	durable medical equipment, home health services, aerosolized drug therapy, transportation to health care, HIV prevention education for families. homemaker services, personal care services, home intravenous therapy, in-home diagnostic testing, case management, and child care
New York^	durable mediil equipment, home health services, day treatment services, homemaker services, personal care services, home intravenous therapy, and in-home diagnostic testing
North Carolina	mediil care, mental health counseling, homemaker services, hospice care. home-delivered meals, HIV support groups. personal care, nursing cam. substance abuse services, adult day care, transportation services, case managers. child care. podiatry services, dental care, home health services, respite care, benefits advocacy, housing referrals, and legal services
	(Home and community-based services were provided during 1995 through consortia and may be provided on a state-level during 1996.)
Ohio	durable medical equipment, home health services, homemaker services, personal care services, home hospice care, RN visits, and RN assessments
Oklahoma	durable medical equipment, home health services, mental health services, HIV prevention education fur familii, homemaker services, personal care services, home hospice care. and case management
South Dakota	durable medical equipment, home health services, day treatment and partial hospitalization services, aerosolized drug therapy, mental health services, personal care services, and case management
Tennessee	case management (" Eleven diient services were implemented on January 1 , 1996.")
Utah	durable medical equipment, homemaker services, personal care services, in-home diagnostic testing, case management IV drug therapy, and skilled nursing
Washington	dental services, transportation to health care, homemaker services, personal care services, and case management "Home care is provided on a personal care basis with home health/nursing from Medicaid and insurance."
Wyoming	durable medical equipment, aerosolized drug therapy, dental services, transportation to health care. mental health services, home intravenous therapy, and case management

^States with the highest incidence of AIDS.

Source: Robert J. Buchanan, Ph.D., Department of Community Health, University of Illinois, a 1995 survey of state program administrators, Title II of the Ryan White CARE Act. This research was funded by a grant from the Health Care Financing Administration, U.S. Department of Health and Human Services (grant # 18-P-90286/5-01).

services covered by the home and community-based care program in Kentucky was expected to decrease and Michigan responded that the Tile II home and community-based care program may be discontinued in that state during 1996.

Effective Home and Community-Based Care Services

The questionnaire asked the AIDS program directors to list the services that are most effective at meeting the care needs of people with HIV that were covered by the home and community-based care program in their state during 1995. The responses are summarized in Table 44. Among the most frequently mentioned effective home and community-based care services are: case management, personal/attendant care, homemaker/chore services, home I.V. therapy, and transportation.

Title II Beneficiaries and Eligibility Policies

The Ryan White CARE Act did not establish income restrictions for individuals to receive benefits from Title II programs, although the statute did specify that CARE Act programs must be the payer of last resort.[8] Given the absence of federally-set income standards for eligibility, the states have the ability to establish there own financial eligibly criteria for individuals to receive Tile II benefits. The survey asked the AIDS program directors to provide: the number of people receiving services from home and community-based care programs funded by Title II; medical and financial eligibility criteria for services offered by home and community-based care programs; trends in financial eligibility criteria; spend down procedures for eligibility; and any use of waiting lists.

People Receiving Home and Community-Based Care Benefits

The questionnaire asked the AIDS program directors to estimate at the time of the survey (mid 1995) the number of people in their state receiving services from

Table 4-4
Home and Community-Based Care Programs Funded by Tiie II of the Ryan White CARE Act during 1995:
Home and Community-Based Services

	Compared to 1994, the Number of H&CBC Services Covered During 1995 has:	During 1996 the Number of H&CBC Services Covered is Expected to:	The Most Effective H&CBC Services at Meeting the Health Care Needs of People with HIV:
California^	increase in 1995 (due to addition of nutrition services)	remain the same	Comprehensive Nurse Case Management (using the Interdisciplinary Team approach, both nurse and social worker) and attendant care
Delaware^	remain the same	remain the same	homemaker, day treatment, dental services, and ophthalmic services
District of Columbia^	remain the same	remain the same	Home Health/Personal Care aide services
Georgia	remain the same	increase in 1996	none mentioned
Kansas	increase in 1995	remain the same	home health aide
Kentucky	increase in 1995	decrease in 1996	home health services, mental health therapy, primary care, dental care, case management, and transportation
Louisiana	remain the same	remain the same	skilled nurse for I.V., home health aide, and personal care attendant
Maine	remain the same	remain the same	case management
Maryland^	remain the same	remain the same	skilled nursing, in-home HIV therapies, personal care, and chore services
Massachusetts	remain the same	remain the same	homemaker services
Michigan	increase in 1995	no coverage in 1996	personal care/chore services
Minnesota	increase in 1995	remain the same	case management, transportation, early intervention, and health insurance continuation ("although not a "home care" program")
Mississippi	remain the same	remain the same	aerosolized drug therapy and home I.V. therapy
Nevada	increase in 1995	remain the same	transportation to care, housing assistance, home hospice, ase management, personal care services, and homemake
New Hampshire	remain the same	remain the same	varies by client need/status
New Jersey^	increase in 1995	remain the same	routine and specialized nursing home health aide, homemaker and personal care attendant services
New Mexico	increase in 1995	increase in 1996	homemaker/personal care services
New York^	increase in 1995	increase in 1996	'Home health aides account for 73% of the cost of the HIV Home Care Program Services. All services are pre-authorized based on medical needs justification.'
North Carolina	remain the same	remain the same	personal care and respite care
	(Home and community-based services were provided during 1995 through consortia and may be provided on a state-level during 1996.)		
Ohio	remain the same	remain the same (uncertain)	homemaker services, home health aide, and supplier
Oklahoma	increase in 1995	increase in 1996	personal and skilled care
South Dakota	remain the same	remain the same	home health care
Tennessee	increase in 1995	increase in 1996	We only offer case managers during 1995.'
Utah	remain the same	remain the same	personal care and homemaker services
Washington	remain the same	remain the same	case management, dental care, pharmacy assistance, and home care
Wyoming	increase in 1995	increase in 1996	'Case management - case managers are advocates, mothers, and a source of human caring.

^States with the highest incidence of AIDS.

Source: Robert J. Buchanan, Ph.D., Department of Community Health, University of Illinois, a 1995 survey of state program administrators, Title II of the Ryan White CAFE Act. This research was funded by a grant from the Health Dare Financing Administration, U.S. Department of Health and Human Services (grant #18-P-90286/5-01).

home and community-based care programs funded by Title II, with these estimates presented in Table 4-5. The questionnaire also asked the AIDS program directors to estimate how the number of these people receiving home and community-based services in their state during 1995 compared to the number of people receiving services in 1994. As Table **4-5** presents, the AIDS program directors in most states estimated that the number of people receiving services from the home and community-based care programs funded by Tile II increased in 1995 compared to 1994. In addition, the questionnaire asked the AIDS program directors to estimate how the number of people receiving home and community-based care services in their state during 1995 compared to the number of people expected to receive these services during 1996. As Table 4-5 illustrates, the AIDS program directors in most states expect the number of people receiving services provided by home and community-based care programs funded by Title II to increase during 1996.

Medical Eligibility Requirements

The questionnaire asked the AIDS program directors to provide medical eligibility requirements in their state for people to receive home and community-based services funded by Tie II during 1995. As the Table 4-5 documents, most states responded that the individual must be HIV positive to meet medical eligibility requirements. Many states have implemented additional medical criteria, typically relating to physical dependency or requiring assistance with activities for daily living. **For example, medical eligibility criteria** for services provided by home and **community-based** care programs funded by **Title** II in California require that a person be "symptomatic HIV or AIDS and need assistance in at least one area of functioning." Similarly, in the District of Columbia a person must be non-ambulatory "with non-acute

Table 4-5
Home and Community-Based Care Programs Funded by Title II of the Ryan White CARE Act during 1995: Beneficiaries and Eligibility Policies

	Estimates of the Number of People Receiving HCBS from the Title II Program:			Medical Eligibility Requirements for HCBS	To be Financially Eligible for HCBS, Gross Monthly Income during 1995 Cannot Exceed:		Compared to 1993, Financial Eligibility Criteria for HCBS in 1995 have Become:
	1995	1995 Compared to 1994	1996 Compared to 1995		1-Person Household	4-Person Household	
California^	530	remain the same	remain the same	*	**	**	remain the same
	*"Symptomatic HIV or AIDS and need assistance in at least one area of functioning (Karnofsky [scale] of 70 or less)." **"No income requirements. Majority are low income in spend down for Medi-Cal [Medicaid], or are on Medi-Cal but not yet eligible for the AIDS Medi-Cal Waiver."						
Delaware^	107	increase in 1995	increase in 1996	HIV+	$613.33/month	$2,281/month	more restrictive in 1995
District of Columbia^	53	increase in 1995	remain the same	***	not applicable	not applicable ("However, the program targets low-income underserved and uninsured people."	not applicable
	***"Non-ambulatory patients with non-acute conditions related to HIV disease who are unable to receive outpatient primary medical care, but do not require [institutional care].						
Georgia	45	increase in 1995	increase in 1996	no answer	no answer	no answer	no answer
Kansas	44	no answer	increase in 1996	HIV+	300% of federal poverty level		less restrictive in 1995
Kentucky	1,287	increase in 1995	increase in 1996	HIV+, with documented need for services	$22,410/year (300% of federal poverty level)	$45,450/year	less restrictive in 1995
Louisiana	200	increase in 1995	increase in 1996	~	$1,245/month	$2,525/month	less restrictive in 1995
	~Determination of the need for home-based care is completed by a physician.						
Maine	400+	increase in 1995	increase in 1996	HIV+	no income guidelines		remain the same
Maryland^	170	increase in 1995	remain the same	HIV+ plus meet medical criteria for home health (ADL assistance)	$709/month (State sliding scale fee, but no one denied service for inability to pay.)	$1,475/month	more restrictive in 1995
Massachusetts	450	increase in 1995	remain the same	HIV+	$27,000/year	$37,000/year	less restrictive in 1995 (increased to $27,000/yr.
Michigan	60	increase in 1995	decrease in 1996	"They are being revised. The HCBC program may be discontinued."			"No, until very recently."
Minnesota	1,500	increase in 1995	increase in 1996	no medical eligibility criteria	$1,867/month (300% of federal poverty level)	$3,787/month	remain the same
Mississippi	84	increase in 1995	increase in 1996	prescribed by physician	$1,245/month	$2,525/month	remain the same
Nevada	215	increase in 1995	increase in 1996	determined locally by health districts	determined locally (generally up to 300% of federal poverty level)	determined locally	less restrictive in 1995
New Hampshire	40	remain the same	remain the same	no answer	$14,940/year	$30,500/year	remain the same
New Jersey^	510	increase in 1995	remain the same	diagnosis of HIV/AIDS	$2,500/month	$5,000/month	remain the same
New Mexico	250	increase in 1995	increase in 1996	participant in case management and taking at least one drug on formulary	$1,869/month	$1,869/month	more restrictive in 1995
New York^	1,360	increase in 1995	increase in 1996	AIDS or HIV symptomatic illness & chronic medical dependency	$3,666/month	$6,200/month	remain the same
North Carolina	3,000	increase in 1995	increase in 1996	HIV+	Sliding scale reimbursement		remain the same
	(Home and community-based services were provided during 1995 through consortia and may be provided on a state-level during 1996.)						
Ohio	25	increase in 1995	increase in 1996	HIV+	$1,374/month	$3,435/month	remain the same
Oklahoma	50	increase in 1995	increase in 1996	none mentioned	$934/month	$1,894/month	more restrictive in 1995
South Dakota	20	remain the same	remain the same	HIV+	$1,867/month	$3,787/month	remain the same
Tennessee	200	not applicable	increase in 1996	HIV+	No financial criteria for any service~~		not applicable~~
	("During 1995 only case managers were provided. The state initiated 11 different services under H&CBC on January 1, 1996.") ~~"Currently there are no financial restriction. If a subcontractor does charge, they are required to use the sliding scale as determined by HRSA."						
Utah	35	decrease in 1995 (program administration change)	remain the same	medically or chronically dependent	poverty level	poverty level	remain the same
Washington	40	remain the same	remain the same~~~	disabling HIV/AIDS condition	$1,246/month	$2,466/month	remain the same
	~~"Depends on community/regional needs assessments."						
Wyoming	38	increase in 1995	increase in 1996	unable to work and need ADL assistance	$20,430/year	$41,850/year	remain the same

^States with the highest incidence of AIDS.

Source: Robert J. Buchanan, Ph.D., Department of Community Health, University of Illinois, a 1995 survey of state program administrators, Title II of the Ryan White CARE Act. This research was funded by a grant from the Health Care Financing Administration, U.S. Department of Health and Human Services (grant # 18-P-90286/5-01).

conditions related to HIV disease who [is] unable to receive outpatient primary medical care, but [does] not require [institutional care]."

Income Eligibility Requirements

The questionnaire asked the AIDS program directors to provide the maximum monthly income level an individual in a one-person household living in their state could have during 1995 to be eligible for the home and community-based care program. In addition, the AIDS program directors were asked to provide the maximum monthly income a family of four could have during 1995 for an individual within that family to be eligible for the home and community-based care program. These financial eligibility requirements reported by the states are presented in Table 4-5. A few states reported no income requirements for HIV infected people to receive services from the home and community-based care program funded by Title II. As Table 4-5 illustrates, even states that establish income ceilings for eligibility, set generous eligibility standards. This is particularly noticeable if income eligibility standards for services offered by the home and community-based care programs funded by Tile II are compared to income eligibility standards for state Medicaid coverage (the largest payer of AIDS-related care.) For example, during 1993 most individuals with AIDS could not have incomes in excess of $434 per month to receive Medicaid coverage in most states.' Hence, home and community-based care programs funded by Title II can provide services to people infected with HIV who have incomes too high to become eligible for Medicaid coverage. The Title II programs strengthen the public-sector safety net for funding the care needed by people with HIV-related illness.

Trends in Financial Eligibility Criteria

The questionnaire asked the AIDS program directors if financial eligibility criteria in their state for services provided by the home and community-based care program during 1995 have become more restrictive since 1993, providing responses of "more restrictive in 1995," less restrictive in 1995," or "remain the same." While financial eligibility for home and community-based care services funded by Tile II remained the same in many states, these criteria have changed in a number of states as Table 4-5 illustrates. The questionnaire also asked the AIDS program directors if they expected financial eligibility criteria **for the home and community-based care programs** in their state to become more restrictive during 1996. All the states (and the District of Columbia) responding to the survey that provided home and community-based care programs funded by Title II reported that financial eligibility criteria are expected to remain the same during 1996 except for four states. Financial eligibility criteria for the home and community-based care program in Wyoming, New Mexico, and Michigan" are expected to become more restrictive in 1996 and Georgia did not answer this question. (Given the similarity of responses from most states, these data for 1996 are not reported in Table 4-5.)

Spend Down Procedures

The questionnaire asked the AIDS program directors if eligibility determination procedures in their state for services provided by home and community-based care programs include a spend down provision. Spend down was defined on the questionnaire as "allowing the applicant to deduct the cost of medical care from income levels and using this medical-cost adjusted income level for eligibility determination." (Most state Medicaid programs allow spend down when determining

Medicaid eligibility.“) According to the survey responses, only the Title II programs in Maryland, North Carolina, Ohio, and Oklahoma include spend down provisions in the determination of financial eligibility for services provided by home and community-based care programs, while Minnesota reported it “depends on the program.” The other states with home and community-based care programs funded by Title II either did not include spend down provisions in the eligibility process, or spend down was not applicable because the state had no income requirements for eligibility. (Given the similarity of responses from most states, these data for 1996 are not reported in Table 4-5.)

Waiting Lists

The questionnaire asked if there was a waiting list of people in their state waiting to receive services from the home and community-based care program funded by Tile II during 1995. If there was a waiting list, the AIDS program directors were asked to estimate both the number of people currently on the waiting list at the time of the survey and the number of days a person had to wait to receive home and community-based services during 1995. Based on the survey responses, only the Title II program in California reported the use of waiting lists for home and community-based services, with **700** people waiting at the time of the survey. However, in California “those most in need (in advanced stages of HIV disease or unable to function without assistance) are seen or referred to the appropriate sources as soon as possible.” In addition, Michigan responded that while there was no waiting list at the time of the survey, one may be implemented “in the very near future.” (Given the absence of reported waiting lists in all other states, these data are not reported in Table 4-5.)

Coordination with Medicaid

Although the Ryan White CARE Act specifies that Tile II funds must be the payer of last resort, Tile II programs can supplement Medicaid coverage if Medicaid does not cover a needed health service or if a recipient's care needs exceed Medicaid utilization limits.[12] If a state Medicaid program does not cover hospice care, for example, a Medicaid recipient can receive that service through a program funded by the CARE Act, if available. Similarly, if a Medicaid recipient needs more home nursing visits then allowed by the state Medicaid program, programs funded by the CARE Act may pay for additional home nursing care?

The state Medicaid programs and Tile II programs can coordinate services to provide a continuum of care and eliminate duplication of services, serving the care needs of people with HIV diseases more efficiently.[14 15] A study by the National Governor's Association (NGA) examined how the state Medicaid programs and programs funded by Tile II can coordinate to serve people with HIV and AIDS more effectively and efficiently? Among the areas of collaboration identified by the NGA study are: planning and implementing home care services; administering drug reimbursement and assistance programs; administering health insurance continuation programs; cross-training between CARE Act and Medicaid programs; sharing information and protecting client confidentiality; planning, administering and staffing case management services; collaborating through CARE Act program meetings (e.g., Title II statewide advisory committees); and outstationing Medicaid eligibility workers.

The state Medicaid programs typically do not cover and reimburse the home-based, nonmedical social and support services often needed by people with AIDS and HIV disease." [18] The Medicaid Home and Community-Based Care Waiver

programs, however, allow the state Medicaid programs to reimburse medical and other support services provided in the home or community to people with AIDS who would otherwise need institutional care. The state Medicaid programs and the Tiile I and Tile II programs funded by the Ryan White CARE Act can work together to design, develop, and implement these Medicaid Home and Community-Based Care Waiver programs.[19] Developing these Medicaid waiver programs, and coordinating implementation with CARE Act programs, would allow CARE Act funds to be spent on alternative care as well as offer a broader array of home and community-based care services than many state Title II programs can offer due to funding constraints?

Medicaid Home and Community-Based Care Waiver Programs

There are two Medicaid Home and Community-Based Care Waiver programs that can be used to provide nonmedical, social, and support services to people with AIDS. Section 2176 of the 1981 Omnibus Budget Reconciliation Act gives the Health Care Financing Administration (the federal agency with responsibility for Medicaid administration) the authority to waive certain federal Medicaid regulations to allow states to cover home and community-based care targeted to specific groups of Medicaid recipients (such as the disabled) who otherwise would be institutionalized.[21] The Omnibus Budget Reconciliation Act of 1985 amended Section 2176 to allow AIDS-specific waiver programs for home and community-based care? The state Medicaid programs can use either the original waiver program for the elderly and disabled to provide special services to Medicaid recipients with AIDS because of their disability status, or the AIDS-specific waiver program. The expanded home and community-based care services covered through these waiver programs allow Medicaid programs to provide a broad array of medical, personal care, and other nonmedical and social

support services to people with AIDS in their homes? In addition to expanded coverage of services, these waiver programs also permit the states to establish less restrictive financial eligibility criteria for waiver services than used to establish eligibility for the regular Medicaid program, allowing more people with AIDS to receive care."

Title II/Medicaid Utilization Limits

The questionnaire asked the AIDS program directors if the Medicaid program in their state "limits utilization of home-based care (e.g., 50 home health visits per year), do home and community-based care programs funded by Tile II in your state cover the use of these services in excess of the Medicaid limits?" To facilitate responses, the questionnaire provide "yes," "no," and "no Medicaid utilization limits" as possible responses. As Table 4-6 documents, the home and community-based care programs funded by Title II in most states did cover needed services in excess of Medicaid utilization limits during 1995.

Effective Tiile II /Medicaid Coordination

The questionnaire asked the AIDS program directors to "describe effective methods and policies for the coordination and integration of the Medicaid program with the Tile II program in your state." Table 4-6 summarizes their responses. In many states Tile II/Medicaid coordination involves assuring that Title II is the payer of last resort. In Louisiana, for example, the home health agency is required to verify if the patient has coverage by other third-party payers. In Maryland, Title II home care providers also must be approved as Medicaid providers and bill Medicaid for any covered health care that is provided. In New Jersey and Wyoming case managers assist Title II beneficiaries with the Medicaid eligibility process, while in Mississippi the Title II coordinator serves as the gatekeeper for the coordination of Title II benefits with

Table 4-6
Home and Community-Based Care Programs Funded by Title II of the Ryan White CARE Act during 1995: Coordination with the State Medicaid Program

	Do H&CBC Services Funded by Title II Cover the Use of Services in Excess of Any Medicaid Limits?	Effective Methods and Policies for the Coordination d Medicaid and Tii II	Barriers to the Coordination d Medicaid and Tii II
California^			
	"California has an AIDS Medi-Cal [Medicaid] Waiver Program that provides comprehensive nurse case management, home and community-based care to people living with HIV/AIDS who would otherwise require institutional care (Karnofsky [scale] of 60 or less). The Office of AIDS contracts with county health departments and community-based organizations who are certified as AIDS Waiver providers. These agencies subcontract with local home health agencies and other appropriately licensed agencies to provide direct patient care. Title II funding is used to augment an existing state program, the AIDS Case Management Program, which also provides nurse case management and home and community-based care to people with mid to late stage HIV/AIDS (Karnofsky of 70 or less). The Office of AIDS contracts with 37 providers for this program, most of which are also AIDS Waiver providers. Having contracts for both programs allows for continuity of care for individuals as they become eligible for the [Medicaid] AIDS Waiver. Clients on the AIDS Waiver cannot be enrolled simultaneously in the AIDS Case Management Program, which prevents duplication of services.		
	"There may be some lack of coordination between [Title II and] California's Medi-Cal Program [Medicaid].		
Delaware^	yes	quarterly meetings; E-mail	none
District of Columbia*	On August 15, 1995 the Agency for HIV/AIDS requested information from the HCFA concerning thii issue.'	"The position of Home Health Coordinator at DC. CARE will be designed to coordinab services across funding streams."	"On August 15, 1995 the Agency for HIV/AIDS requested information from the HCFA concerning this issue:
Georgia	not applicable	none mentioned	none mentioned
Kansas	yes	no answer to the question	"Both programs try to coordinate with each other when possible."
Kentucky	"Yes - based on [Title II] funding availabilii. We are willing to cover the cost of home health visits whenever these services are not available through Medicaid."	"Anytime a client is eligible for services or benefits (e.g., drugs, health services, etc.) through Medicaid, that makes them ineligible for those same services or benefits from the Title II programs. The programs have worked together to avoid duplication d services."	"The programs are separate and situated in different departments, so bureaucracy sometimes makes things more difficult than they should be, or at least slows down interaction. However, on the whole, there is good communication between the programs. Sometimes, the fact that we are in different departments means that we aren't as aware of the hanges *taking* place in each other's programs.'
Louisiana	"Yes, that is a primary goal we [Title II] provide gap coverage."	"At the time of referral, the home health agency is required to verify the extent of coverage by any and all third party payers. They must track visits and provide monthly summary of visits remaining."	"The greatest barrier is effective communication concerning status between HPO and homeheanhagency. Clients don't always know they have Medicaid, there is a delay before acceptance is granted, and record keeping is very labor intensive."
Maine	no Medicaid utilization limits	"AIDS Targeted Case Management is a Medicaid reimbursable service; Medicaid Waiver for home-based care currently being sought.=	"Lack of front line communication between case managers *and* Medicaid eligibility workers."
Maryland^	yes	"Medicaid staff participate in Maryland AIDS Policy Workgroup; Tii II vendors are required to be approved as Medicaid providers and must bill [Medicaid] for covered services; Title II staff also provido AIDS-related expenditure analyses for Medicaid, are developing a cooperative qualii assurance program, andareworkingwith Medicaid HMO staff in training and delivery issues.'	none
Massachusetts	no	"Medicaid does not cover these [homemaker] services."	no answer to the question
Michigan	We have not allocated any additional [Title II] resources to home health other than those expended in April, 1995. Thiiwasdueto a significant shortfall in Title II resources in Michigan.'		
Minnesota	yes	We subcontract drug, insurance, and dental programs with the state welfare agency."	"None, other than increasing demand and health care/welfare reform uncertainties
Mississippi	yes	"Coordinator has 8 years experience as a Medicaid specialist. Coordinator serves as the gatekeeper for coordination d benefits with Medicaid..	"Lack d cooperation from Mediiid program.'
Nevada	no (this has not been an issue)	"The Medicaid AIDS Coordinator is a member of the State AIDS Task Force (by appointment in the by-laws), and this keeps Medicaid a steady member of the team. We also share an electronic verification d eligibility system with Medicaid that assists in getting clients on the [Title II drug program] without delay. Case workers for Medicaid and CBOs receive updates and information from Ryan White and Medicaid:	"The real barriers are the scope of coverage and time lags based on state law. Institutional barriers are not significant."
New Hampshire	yes	"One case manager for Title II and Medicaid. Medicaid pays for this individual."	Lack of personnel.

Table 4-6
Home and Community-Based Care Programs Funded by Title II of the Ryan Whii CARE Act during 1995: Coordination with the State Medicaid Program

	Do H&CBC Services Funded by Title II Cover the Use of Services in Excess of Any Medicaid Limits?	Effective Methods and Policies for the Coordination of Medicaid and Title II	Barriers to the Coordination of Medicaid and Title II
New Jersey^	yes	"The HIV Home Care Program is a short term program in which the case manager places the client on the program while seeking out Medicaid entitlements far the client."	"One barrier is the cumbersome [Medicaid] paperwork which increases the length of time from the client's assessment [for eligibility] to actual enrollment into a Medicaid program."
New Mexico	yes	to utilize all Medicaid dollars; utilize other funds; use HIV/AIDS waiver funds	Medicaid eliiibilii doesn't always remain: providers reluctant to bill additional funding sources; system not set up for constant interaction.
New York^	no Medicaid utilization limits	an individual is ineligible for HIV Home Care if covered by Medicaid; eligibility coordinated through EMEVS at intake and at each recertification; by policy HIV Home Care services coverage is less than Medicaid to encourage transition to Medicaid: if a person has Medicaid spenddown requirements, the HIV Uninsured Care Programs will pay for medical care up to the spenddown requirement each month	"There is a need for a monthly electronic eligibility verification match for improved efficiency in preventing dual enrollment." "NOTE: a weekly match began 4/96."
North Carolina	yes	"The AIDS Care Branch has an interagency agreement with Medicaid to manage the Medicaid HIV case management program and the Medicaid AIDS Home and Community-Based Care services waiver."	no answer to the question
	(Home and community-based services were provided during 1995 through consortia and may be provided on a state-level during 1996.)		
Ohio	yes (uncertain)	"As soon as PWA are Medicaid eligible, (esp. clients in ADAP), we suggest they sign up for Medicaid. We have [Medicaid] spenddown in Ohio so some clients are not Medicaid eligible, but are eligible for ADAP. When they meet spenddown or become Medicaid eligible, we have Human Services reimburse our ADAP. We work with Human Services to be sure our ADAP prices are in line. We have access to Human Service's database. We make sure that ADAP and [Medicaid] cover the same medications."	"Medicaid spenddown -- difficult to understand and difficult for some clients to meet [the spendddown requirements], where clients go on and off Medicaid."
Oklahoma	yes	no answer to this question	imited Medicaid-covered services; reorganization of state Medicaid agency; and budget cuts
South Dakota	yes	no answer	no answer to this question
Tennessee	yes, "we can use [Title II] for anything [Medicaid] does not cover.	'In January, 1994 we dropped Medii and implemented TennCare - a managed care plan. The vast majority of those with HIV are eligible for coverage. Prior to this, we had 100% of our [Title II] money in drug assistance. During early 1995 a new [state] administration took over and he entire Ryan White program is being restructured under new directors. Thus barriers/positives are yet unknown.'	
Utah	) Medicaid utilization limits, ■ but we do supplement Medicaid services and they must be cost-effective compared to institutional care."	'Up until this year the drug therapy program (state and local funds) was administered through Medicaid."	"Medicaid has no mandate to coordinate; therefore other priorities within [Medicaid] take precedence."
Washington	yes	"Very separate in Washington. Actual services are coordinated where eligibility and coverage for care must be clarified."	"They are administered by two different agencies. Medicaid is the Department of Social and Health Services and Title II is by local AIDSNET regional entities along with the Department of Health.
Wyoming	"Probably not - [Title II] receives only limited funding:	As soon as the client signs up for Ryan White, the case manager sits down and outlines procedures for getting Medicaid. even helping to fill out the paperwork."	no answer to this question
States with the highest incidence of AIDS.			

ource: Robert J. Buchanan, Ph.D., Department of Community Health, University of Illinois. a 1995 survey of state rogram administrators, Title II of the Ryan White CARE Act. This research was funded by a grant from the ealth Care Financing Administration. U.S. Department of Health and Human Services (grant # 18-P-90286/5-01).

Medicaid coverage. In North Carolina the AIDS Care Branch (Title II) has "an interagency agreement with Medicaid to manage the Medicaid HIV case management program and the Medicaid Home and Community-based services waiver." The Tile II program in New Mexico reported that it utilizes HIV/AIDS waiver funds.

In California the Tffle II program contracts with organizations that also are certified as providers for the Medicaid AIDS waiver program for home and community-based care. Tie II funding also supplements an existing state program (AIDS Case Management Program) that provides nurse case management and home and community-based care services to people with mid to late stage HIV/AIDS. Most of the providers for this state program are also Medicaid AIDS waiver providers. Because the Title II program has contracts with providers that also serve the Medicaid AIDS waiver program and the AIDS Case Management Program, continuity of care is not interrupted for most individuals as they become eligible for the Medicaid AIDS waiver program. To promote continuity of care as people become Medicaid eligible, as well as help assure that Title II is the payer of last resort, the home and community-based care programs funded by Title II should contract with Medicaid-certified service providers.

Barriers to Title II/Medicaid Coordination

The questionnaire asked the AIDS program directors to "describe any barriers to the coordination and integration of the Medicaid program with the Title II program in your state." As Table 4-6 presents, one barrier to coordination and integration results from administration of the two programs by different state agencies. AIDS program directors in other states noted that the Medicaid eligibility/application process is

difficult and time consuming, while other directors mentioned limited Medicaid coverage of services.

Summary and Discussion

Public programs, particularly the state Medicaid programs, pay for the health services provided to most people with AIDS and a significant percentage of people infected with HIV.[25] However, the Medicaid programs establish restrictive eligibility criieria, requiring during 1993 that incomes be below $434 per month in most states? Programs funded by the Ryan White CARE Act provide services to people with AIDS and HIV infection with higher income levels, broadening and strengthening the public-sector safety net for financing HIV-related health care. This paper focused on the home and community-based care programs funded by Tie II of the CARE Act, presenting data on the home and community-based services covered, medical and financial eligibility criteria for these services, and coordination of the Title II programs with the state Medicaid programs.

The study identified a range of home and community-based care services funded by Tile II in various states during 1995. Among the most effective services identified by the study are: case management, personal/attendant care, homemaker/chore services, home I.V. therapy, and transportation.

The study also identified the medical and financial criieria necessary for individuals to become eligible for home and community-based services. The study documents that the state Tile II programs have established generous income eligibility standards for services provided by the home and community-based care programs, especially when compared to Medicaid eligibility standards. Hence, home and community-based care programs funded by Title II can provide services to people

infected with HIV who have incomes too high to become eligible for Medicaid coverage. The Tile II programs strengthen the public-sector safety net for funding the care needed by people with HIV-related illness.

Coordination of the Tile II programs with the Medicaid Home and Community-Based Care Waiver programs will increase the range of services available to people with AIDS and HIV infection while conserving limited Tile II resources. Contracting with Medicaid-certified providers of home and community-based services will allow the Tile II programs to promote the continuity of care as patients become eligible for Medicaid, as well as help assure that Title II is the payer of last resort.

Generous eligibility criteria and coverage of a broad array of home health, personal care, and support services by the home and community-based care programs allows Tffle II and other CARE Act programs to strengthen the public-sector safety net for financing the care needed by people with HIV-related illness. Title II programs provide needed care to people with HIV disease before they become eligible for Medicaid or Medicare? Generous eligibility criieria (or no income restrictions in some states), however, can become a double-edged sword. If federal funding for Title II programs is not sufficiently increased to keep up with the increasing number of people expected to receive benefits from Title II programs, or if future federal Medicaid reform allows the states to establish even more restrictive Medicaid eligibility standards, then the Title II programs may not be able to provide services for all eligible people. This could result in the use of waiting lists, reduced services, some other forms of rationing, or the implementation of more restrictive eligibility criieria. For example, financial shortfalls have jeopardized the home and community-based care program in Michigan. If federal funding for Title II programs in the future does not

keep pace with the expected increase in the number of people eligible for Tile II services, then the public-sector safety net for financing HIV-related care will be weakened.

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6. Centers for Disease Control and Prevention, HIV/AIDS Surveillance Report, 1995; 7(no.2): I-39. Figure 1: Male adult/adolescent AIDS annual rates per 100,000 population, for cases reported in 1995, United States.

7. Although North Cardina reported that Tiie II funds were not used in that state to implement a home and community-based care program, these services were provided by Tie II HIV consortia. Data on the home and community-based services provided by HIV consortia were included in North Carolina's response to the home and community-based care survey and these data are reported in Tables 3 through 6 of this paper. North Cardina may implement a state-level home and community-based care program using Tie II funds during 1996.

6. See note 3.

9. Buchanan, R. "Medicaid Eligibility Pdicies for People with AIDS." Social Work in Health Care Vol.23,No.2(1996): 1541.

10. The home and community-based care program funded by Tie II in Michigan may be discontinued during 1996 according to the survey response from that state.

11. See note 9.

12. See note 3.

13. See note 3.

14. See note 3.

15. Buchanan, R. "Medicaid Policies for Home Care and Hospice Care Provided to Medicaid Recipients with AIDS." AIDS and Public Policy Journal. Vol. 10, No. 4 (1996): 221-237.

16. See note 3.

17. See note 3.

18. See note 15.

19. See note 3.

20. See note 3.

21. Miller, N. 'Medicaid 2176 Home and Community-Based Care Waivers.' Health Affairs. Vol. 11, No. 4 (1992): 162-171.

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22. Jacobson, P., Lindsey, P. and Pascal, A. AIDS-Specific Home and Communltv-Based Waivers for the Medicaid Population (Santa Monica, CA: Rand Corp., 1989).

23. see Buchanan, R. "Medicaid Pdicies for Home Care and Hospice Care Provided to Medicaid Recipients with AIDS." AIDS and Public Pdicv Journal. Vd. 10, No. 4 (1996): 221-237, Table 1 for a listing of selected home and community-based services provided to people with AIDS through Medicaid waiver programs.

24. See note 9.

Also see Congressional Research Service. Medicaid Source Book: Backaround Data and Analysis (A 1993 Update) (Washington, D.C.: U.S. Government Printing Office, 1993).

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26. See note 9.

27. For a person with HIV illness to become eligible for Medicare requires meeting eligibility criteria for Social Security Disability Insurance (SSDI), including disability status, sufficient work-related history, and a 29-month waiting period (5 months from disability status for SSDI payment to begin, then 24 additional months for Medicare coverage to begin). (See Baily, M., Bilheimer, L, Woolridge, J., Langwell, K, and Greenberg, W. "Economic Consequences for Medicaid of Human Immunodeficiency Virus Infection.' Health Care Financina Review (1990 Annual Supplement): 97-108.

Chapter 5
Health Insurance Continuation Programs Funded by Title II of the Ryan White CARE Act[a]

Introduction

The Ryan White Comprehensive AIDS Resource Emergency (CARE) Act (Public Law 101-381) was enacted in August, 1990 to improve both the quality and availability of care for people with HIV disease and their families.' The original legislation authorized: grants to metropolitan areas with the largest number of AIDS cases to help provide emergency services (Title I); grants to the states to improve the quality, availability, and organization of health and related support services (Title II); grants to state health departments for AIDS early intervention services (Title Ill-a) and community-based primary care facilities (Title Ill-b); and grants for research and evaluation initiatives, including demonstration programs for pediatric AIDS research (Title IV).[2] Title II of the CARE Act allows states to allocate funds among any or all of four areas to: cover home-based health services, provide medication and other treatments, continue private health insurance coverage, or fund HIV care consortia.[3]

Background

Among people living with AIDS who have private insurance, 71 percent had their coverage provided by their employers.[4] However, 50 percent of people who were employed before a diagnosis of HIV-related illness stopped working within two years of the onset of the first symptoms.[5] As their illness progresses to the point where they stop working, employment-based, private health insurance may stop for people with AIDS just when their health care needs intensify.

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The Consolidated Omnibus Budget Reconciliation Act of 1985 (P.L. 99-272) requires employers with 20 or more employees that offer a group health plan to continue that coverage for 18 months at the worker's expense (up to 102 percent of the premium) upon termination of employment.[6] The Omnibus Budget Reconciliation Act of 1989 (OBRA 89, P.L. 101-239) provided for an extension of coverage at the worker's expense up to 29 months (at up to 150 percent of the premium after the 18th month) for people who have disabilities when employment was ended.' OBRA 89 allows for the continuation of private health insurance coverage for workers forced to leave employment due to disability as they completed the 29 month waiting period before Medicare coverage begins.'

However, with the end of employment, a person living with AIDS may not be able to afford these premiums and private health coverage would lapse. The objective of this paper is to identify how the states are using Tile II funds to implement health insurance continuation programs. The paper identifies states that have implemented health insurance continuation programs with Tile II funds, the health insurance options offered, and medical and financial eligibility criteria.

Methodology

To identify how the states are using Tile II funds to implement health insurance continuation programs, state AIDS program directors were surveyed. The names and addresses of these directors in each state were obtained from the National Alliance of State and Terriiorial AIDS Directors.[9] In addition, the address file was updated with the names and addresses of AIDS program directors obtained from the Health Resources and Services Administration of the federal government.'*

Survey Process

A health insurance continuation questionnaire was mailed to these AIDS program directors in May, 1995. Three additional mailings of the questionnaires were sent to the states not participating in the survey. When the survey was completed in early 1996, AIDS program directors (or their staffs) in 49 states and the District of Columbia provided data (no reply was received from Rhode Island). The survey responses were summarized into tables and mailed to the AIDS program directors for verification and updates in April, 1996. Updates and any additional information received during the verification process were added to the final tables used in this paper.

Incidence of AIDS

The incidence of AIDS and HIV infection varies widely among the states. Since the focus of this paper is the implementation of health insurance continuation programs funded by Tile II during 1995, state-level AIDS rates per 100,000 population for 1995 were used to put state-level policies for health insurance continuation programs into the context of the incidence of AIDS. The map for male adults/adolescent AIDS annual rates was used for this study to present the incidence of AIDS throughout the United States, with each state assigned to one of our four AIDS-incidence categories." To illustrate the incidence of AIDS throughout the United States, the states were classified according to reported cases: highest incidence of AIDS (75 or more AIDS cases per 100,000 population); high incidence (50 to 74.9 AIDS cases per 100,000 population); medium incidence (25 to 49.9 AIDS cases per 100,000 population) or low incidence (0 to 24.9 AIDS cases per 100,000

Table 5-1:
Categorization of the States by AIDS Incidence Rates for Males (1995)

LOW INCIDENCE (Less than 25.0 cases per 100,000 population): Alaska, Arkansas, Idaho, Iowa, Indiana, Kentucky, Maine, Minnesota, Montana,Nebraska, New Hampshire, New Mexico, North Dakota, Ohio, Oklahoma, South Dakota, Utah, Vermont, West Virginia, Wisconsin, and Wyoming.

MEDIUM INCIDENCE (25 - 49.9 cases per 100,000 population): Alabama, Arizona, Colorado, Illinois, Kansas, Massachusetts, Michigan, Mississippi, Missouri, North Carolina, Oregon, Pennsylvania, Rhode Island, Tennessee, Virginia, and Washington.

HIGH INCIDENCE (50 - 74.9 cases per 100,000 population): Georgia, Hawaii, Louisiana, Nevada, South Carolina, and Texas.

HIGHEST INCIDENCE (75 and over cases per 100,000 population): California, Connecticut, Delaware, District of Columbia, Florida, Maryland, New Jersey, and New York.

population). Table 5-1 summarizes the categorization of the states by the incidence of AIDS.

Health Insurance Continuation Programs

Table 5-2 presents the states that did not implement health insurance continuation programs with Tie II funds during 1995. However, as Table 5-2 illustrates, HIV consortia funded by Tile II assisted with the continuation of health insurance in some of these states and other states reported that state-funded programs cover the continuation of health insurance. The states that reported implementing health insurance continuation programs with Tile II funds during 1995 are presented in Table 5-3.[12]

The questionnaire asked the AIDS program directors if Tile II funds were used during 1995 for the payment of: health insurance premiums, health insurance copayments or coinsurance, health insurance deductibles, or "other health insurance costs (please explain)." The health insurance continuation policies funded by Title II and implemented in the states are summarized in Table 53. As Table 5-3 illustrates, all of the states (except Wisconsin) used Title II funds to pay for health insurance premiums, with a few states paying deductibles and/or copayments or coinsurance as well. The Title II program in Minnesota responded that in addition to health insurance premiums, dental insurance was covered during 1995. The Title II program in Wisconsin reported that Title II funds were used during 1995 for the costs of administering the health insurance continuation program and state funds were used to pay the health insurance premiums.

Table 5-2
States Not Offering Continuity of Health Insurance Coverage
Funded by Title II of the Ryan White CARE Act during 1995

	States Not Offering Continuity of Private Health Insurance Coverage Funded by Title II of the Ryan White CARE Act during 1995
Alabama	The Title II program in Alabama did not offer assistance with private health insurance coverage during 1995
Alaska	The Title II program in Alaska offered assistance with private health insurance coverage through the consortia program
Arizona	The Title II program in Arizona did not offer assistance with private health insurance coverage during 1995
Arkansas	The Title II program in Arkansas offered assistance with private health insurance coverage through the consortia program
Connecticut^	Connecticut provides continuity of private health insurance through a state-funded health insurance program
District of Columbia^	The Title II program in the District of Columbia did not offer assistance with private health insurance coverage during 1995
Idaho	The Title II program in Idaho did not offer assistance with private health insurance coverage during 1995
Indiana	The Title II program in Indiana did not offer assistance with private health insurance coverage during 1995
Iowa	The Title II program in Iowa did not offer assistance with private health insurance coverage during 1995
Maine	The Title II program in Maine did not offer assistance with private health insurance coverage during 1995
Maryland^	The Title II program in Maryland did not offer assistance with private health insurance coverage during 1995 ("Maryland has had a state-funded program to do this since 1990.")
Massachusetts	The Title II program in Massachusetts did not offer assistance with private health insurance coverage during 1995
Michigan	Michigan provides continuity of private health insurance through a state-funded health insurance program
Mississippi	The Title II program in Mississippi did not offer assistance with private health insurance coverage during 1995
Missouri	The Title II program in Missouri did not offer assistance with private health insurance coverage during 1995
Nebraska	The Title II program in Nebraska did not offer assistance with private health insurance coverage during 1995
Nevada	The Title II program in Nevada did not offer assistance with private health insurance coverage during 1995
New Hampshire	The Title II program in New Hampshire plans to implement coverage of insurance payments during 1996 as a cost reduction strategy for drug reimbursement.
New York^	The Title II program in New York did not offer assistance with private health insurance coverage during 1995
North Carolina	The Title II program in North Carolina did not offer assistance with private health insurance coverage during 1995,
North Dakota	The state legislature in North Dakota created a state fund for the continuation of private health insurance
Ohio	The Title II program in Ohio did not offer assistance with private health insurance coverage during 1995, but plans to do so during 1996
Oklahoma	The Title II program in Oklahoma did not offer assistance with private health insurance coverage during 1995
Oregon	The Title II program in Oregon did not offer assistance with private health insurance coverage during 1995, but this program is under study for 1996
Pennsylvania	"Not applicable because Pennsylvania does not administer these programs directly with Title II funds." [Individual consortia may provide these services in Pennsylvania.]
Rhode Island	no response to the survey
South Carolina	HIV care consortia may provide this service in South Carolina, but the Title II program in South Carolina did not fund a separate health insurance program during 1995
Tennessee	The Title II program in Tennessee did not offer assistance with private health insurance coverage during 1995, although consortia may fund this service.
Texas	These services are combined with Title II HIV Care consortia in Texas
Utah	The Title II program in Utah did not offer assistance with private health insurance coverage during 1995, but may during 1996 if there is increased funding
Vermont	A state-funded program in Vermont covers private health insurance continuation
Washington	The Title II program in the State of Washington did not offer assistance with private health insurance coverage during 1995 (A state-funded program covers health insurance continuation.)
West Virginia	The Title II program in West Virginia did not offer assistance with private health insurance coverage during 1995

^States with the highest incidence of AIDS.

Source: Robert J. Buchanan, Ph.D., Department of Community Health, University of Illinois, a 1995 survey of state program administrators, Title II of the Ryan White CARE Act. This research was funded by a grant from the Health Care Financing Administration, U.S. Department of Health and Human Services (grant # 18-P-90286/5-01).

Table 5-3
Health Insurance Continuation Funded by Title II of the Ryan White CARE Act during 1995: Beneficiaries and Eligibility Policies

	Title II Funds Were Used During 1995 to Pay for the Following Health Insurance Coverage:	Estimates of the Number of People Receiving Private Health Insurance Benefits Funded by the Title II Program: 1995	1995 Compared to 1994	1996 Compared to 1995	Medical Eligibility Requirements for Private Health Insurance Benefits	To be Financially Eligible for Benefits, Gross Monthly Income during 1995 Cannot Exceed: 1-Person Household	4-Person Household
Alaska	H.I. premiums	10	slight increase in 1995	increase in 1996	HIV+	"Low income" and unable to pay	
	(The Title II program in Alaska offered assistance with private health insurance coverage through the consortia program)						
Arkansas	H.I. premiums and copay/coinsurance	200	increase in 1995	increase in 1996	HIV+	$12,580/year	$25,520/year
	(The Title II program in Arkansas offered assistance with private health insurance coverage through the consortia program)						
California^	H.I. premiums	506	increase in 1995	remain the same	disabled & unable to work full time due to HIV/AIDS	$1,557/month	$3,157/month
Colorado	H.I. premiums	26	increase in 1995	remain the same	HIV+ or AIDS	$1,867/month	$3,750/month
Delaware^	H.I. premiums and deductibles	15	remain the same	decrease in 1996	HIV+	$1,134.67/month	$2,281.67/month
Florida^	H.I. premiums	716	increase in 1995	increase in 1996	HIV symptomatic or AIDS	$1,559/month	$3,163/month
Georgia	H.I. premiums	200	increase in 1995	increase in 1996	diinosis d HIV dii	200% of federal poverty level	200% of federal poverty level
Hawaii	H.I. premiums	45/month 82/year (595 per month/year)	remain the same	remain the same	HIV+ and unable to work (or cut hours) due to symptomatic HIV	$2,115/month	$4,254/month
Illinois	H.I. premiums	175	increase in 1995	increase in 1996	disabled due to HIV or diagnosed with AIDS	$1,245/month (twice federal poverty level)	$2,525/month
Kansas	H.I. premiums	14	remain the same	increase in 1996	disabled due to HIV infection	300% of federal poverty level	300% of federal poverty level
Kentucky	H.I. premiums	130	increase in 1995	increase in 1996	HIV+	$22,410/year	$45,450/year
Louisiana	H.I. premiums	116	increase in 1995	increase in 1996	disabled from HIV disease or AIDS	$1,027/month	$2,083/month
Minnesota	H.I. premiums and dental insurance	136	increase in 1995	decrease* in 1996	HIV+ (1996)	$1,867.50/month	$3,787.50/month
	**Enrollment in 1996 will significantly decrease because of a significant increase of state funding for the program. Enrollment in our entire insurance program will increase from 1995 to 1996 but proportionately less of it will be paid with Title II funds:						
Montana	H.I. premiums, copay/coinsurance, and deductibles	5	remain the same	remain the same	HIV+	$623/month	$1,263/month
New Hampshire	The Title II program in New Hampshire plans to implement coverage d insurance payments during 19 as a cost reduction strategy for drug reimbursement.						
New Jersey^	H.I. premiums	30**	not applic.**	increase in 1996	a diagnosis d AIDS/HIV+	$2,500/month	$5,000/month
	**the program was recently implemented						
New Mexico	H.I. premiums	70	increase in 1995	increase in 1996	participant in case management	$1,246/month~ ~below 200% of the federal poverty level	~
South Dakota	H.I. premiums, copay/coinsurance, and deductibles	5	increase in 1995	remainthe same	HIV+	$1,867.50/month	$3,787.50/month
Virginia	H.I. premiums	46	increase in 1995	increase in 1996	doctor's statement, COBRA policy	$14,50fyr.~~ ~~below 200% of the federal poverty level	$27,000/yr.~~
Win	Other~~~	65 (1996)	increase in 1995	increase in 1996	documentation of HIV+	$1,290/month (1996)	$2,600/month (1996)
	~~Title II funds are used for the cost of administering insurance programs (salary and associated position costs), state funds are used to pay the premiums						
Wyoming	H.I. premiums, copay/coinsurance. and deductibles	4	increase in 1995	increase in 1996	HIV+	$20,430/year	$41,850/year
^States with the highest incidence of AIDS.							

Source: Robert J. Buchanan, Ph.D., Department d Community Health, University d Illinois, a 1995 survey d state program administrators, Title II of the Ryan White CARE Act. This research was funded by a grant from the Health Care Financing Administration. U.S. Department d Heal61 and Human Services (grant # 18-P-90286/5-01).

Title II Beneficiaries and Eligibility Policies

The Ryan White CARE Act did not establish income restrictions for individuals to receive benefits from Title II programs.[13] Given the absence of federally-set income standards for eligibility, the states have the ability to establish there own financialeligibly criteria for individuals to receive Tile II benefits. The survey asked the AIDS program directors to provide: the number of people receiving assistance from health insurance continuation programs funded by Title II; medical and financial eligibility criteria for benefits offered by the program; trends in financial eligibility criteria; spend down procedures for eligibility; and any use of waiting lists.

People Receiving Health Insurance Continuation Assistance

The questionnaire asked the AIDS program directors to estimate at the time of the survey (mid 1995) the number of people in their state receiving assistance from the health insurance continuation program funded by Tile II, with these estimates presented in Table 5-3. The questionnaire also asked the AIDS program directors to estimate how the number of these people receiving assistance with health insurance continuation in their state during 1995 compared to the number of people receiving assistance in 1994. As Table 53 presents, the AIDS program directors in most states estimated that the number of people receiving assistance from the health insurance continuation program funded by Title II increased in 1995 compared to 1994. In addition, the questionnaire asked the AIDS program directors to estimate how the number of people receiving assistance **with health insurance continuation** in their state during 1995 compared to the number of people expected to receive this assistance during 1996. As Table 53 illustrates, the AIDS program directors in most states

expect the number of people receiving benefits from the health insurance continuation program funded by Title II to increase during 1996.

Medical Eligibility Requirements

The questionnaire asked the AIDS program directors to provide medical eligibility requirements in their state for people to receive assistance with health insurance continuation funded by Tile II during 1995. As the Table 5-3 documents, most states responded that the individual must be HIV positive to meet medical eligibility requirements. Many states have implemented additional medical criteria, typically relating to disability from HIV/AIDS. For example, Hawaii responded to the survey that a person must be infected with HIV and unable to work, or have reduced hours of employment, due to symptomatic HIV to meet medical eligibility requirements in that state for the health insurance continuation program funded by Tile II.

Income Eliglbllity Requirements

The questionnaire asked the AIDS program directors to provide the maximum monthly income level an individual in a one-person household living in their state could have during 1995 to be eligible for the health insurance continuation program. In addition, the AIDS program directors were asked to provide the maximum monthly income a family of four could have during 1995 for an individual within that family to be eligible for the health insurance continuation program. These financial eligibility requirements reported by the states are presented in Table 5-3. As Table 5-3 illustrates, these income levels are relatively generous, especially when compared to income eligibility standards for state Medicaid coverage (the largest payer of **AIDS-**related care.) For example, during 1993 most individuals with AIDS could not have incomes in excess of $434 per month to receive Medicaid coverage in most **states.**[14]

Hence, health insurance continuation programs funded by Tile II can assist with the purchase of health insurance coverage for people infected with HIV who have incomes too high to **become eligible for Medicaid coverage.**

Trends in Financial Eligibility Criteria

The questionnaire asked the AIDS program directors if financial eligibility criieria in their state for assistance provided by the health insurance continuation program during **1995** have become more restrictive since **1993,** providing responses of "more restrictive in **1995,"** less restrictive in 1995," or "remain the same." while financial eligibility requirements for the health insurance continuation program funded by Tile II remained the same in most states, these criteria have changed in a number of states as Table **5-4** illustrates. The questionnaire also asked the AIDS program directors if they expected financial eligibility criieria for the health insurance continuation program in their state to become more restrictive during 1996. All the states responding to the survey that provided health insurance continuation programs funded by Title II reported that financial eligibility criteria are expected to remain the same during **1996,** except for Virginia which expects eligibility **criteria** to become less restrictive in 1996.

Spend Down Procedures

The questionnaire asked the AIDS program directors if eligibility determination procedures in their state for assistance provided by the health insurance continuation program include a spend down provision. Spend down was defined on the questionnaire as "allowing the applicant to deduct the cost of medical care from income levels and using this medical-cost adjusted income level for eligibility determination." (Most state Medicaid programs allow spend down when determining Medicaid eligibility."> According to the survey responses, only the Tile II programs

Table 5-4
Health Insurance Continuation Funded by Tiie II of the Ryan White CARE Act during 1995:
Eligibilll Criteria and Waiting Lists for Eligibility

	Compared to 1993, Financial Eligibility Criteria for Health Insurance Coverage in 1995 have Become:	During 1996 Financial Eligibility Criteria for Health Insurance Coverage is Expected to Become:	Is There a Waiting List of People for Eligibility for Health Insurance Coverage During 1995?	If There is a Waiting List for Eligibility for Health Insurance Coverage, Estimate the Following for 1995:	
				Number of People on the Waiting List	Length of Time on the Waiting List
Alaska	more restrictive in 1995	remain the same	no	not applicable	not applicable
	(The Title II program in Alaska offered assistance with private health insurance coverage through the consortia program)				
Arkansas	remain the same	remain the same	no	not applicable	not applicable
	(The Title II program in Arkansas offered assistance with private health insurance coverage through the consortia program				
California^	remain the same	remain the same	no	not applicable	not applicable
Colorado	no insurance program in 1993	remain the same	yes	about 30*	•
	*"Our waiting list is intentionally kept at a low number because there is so little turnover in the program that we feel it unfair to offer hope for getting on the program when there is so little chance. In Colorado 26 slots from different parts of the state are available to bs filled. When these are full. we do not add slots. We are working with the state legislature to provide enough money to double the program. Until that is done, the cap will remain at 26."				
Delaware^	remain the same	remain the same	no	not applicable	not applicable
Florida"	less restrictive in 1995	remain the same	no	not applicable	not applicable
Georgia	remain the same	remain the same	no	not applicable	not applicable
Hawaii	remain the same	remain the same	no	not applicable	not applicable
Illinois	remain the same	remain the same	no	not applicable	not applicable
Kansas	remain the same	remain the same	no	not applicable	not applicable
Kentucky	less restrictive in 1995	remain the same	no	not applicable	not applicable
Louisiana	less restrictive in 1995	remain the same	no	not applicable	not applicable
Minnesota	remain the same	remain the same	no	not applicable	not applicable
Montana	remain the same	remain the same	no	not applicable	not applicable
New Hampshire	The Title II program in New Hampshire plans to implement coverage of insurance payments during 1996 as a cost reduction strategy for drug reimbursement.				
New Jersey^	not applicable	remain the same	no	not applicable	not applicable
New Mexico	more restrictive in 1995	remain the same	no	not applicable	not applicable
South Dakota	remain the same	remain the same	yes**	0**	not applicable
			**limit is 5, none on the list at this time		
Virginia	remain the same	less restrictive in 1996	no	not applicable	not applicable
Wisconsin	remain the same***	remain the same***	no***	not applicable***	not applicable***
	***Title II funds are used for the cost of administering insurance programs, state funds are used to pay the premiums				
Wyoming	remain the same	remain the same	no	not applicable	not applicable

'States with the highest incidence of AIDS.

Source: Robert J. Buchanan, Ph.D., Department of Community Health, University of Illinois, a 1995 survey of state program administrators, Title II of the Ryan White CARE Act. This research was funded by a grant from the Health Care Financing Administration, U.S. Department of Health and Human Services (grant # 18-P-90286/5-01).

in Arkansas, Georgia, and Minnesota included spend down provisions in the determination of financial eligibility for assistance provided by health insurance continuation program during 1995. (Given the similarity of responses from most states, these data are not reported in Table 54.)

Waiting Lists

The questionnaire asked the AIDS program directors if there was a waiting list of people in their state waiting to receive assistance from the health insurance continuation program funded by Title II during 1995. If there was a waiting list, the AIDS program directors were asked to estimate both the number of people currently on the waiting list at the time of the survey and the number of days a person had to wait to receive health insurance continuation benefits during 1995. Based on the survey responses, only the Title II programs in Colorado and South Dakota reported the use of waiting lists for the health insurance continuation program. (See Table 5-4.) Colorado reported that "our waiting list is intentionally kept at a low number because there is so little turnover in the program that we feel it unfair to offer hope for getting on the program when there is so little chance. In Colorado 26 slots from different parts of the state are available to be filled. When these are full, we do not add slots." South Dakota responded that it limits the number of people waiting for assistance from the health insurance continuation program to five, although at the time of the survey no one was on the waiting list.

Summary and Discussion

Public programs, particularly the state Medicaid programs, pay for the health services provided to most people with AIDS and a significant percentage of people infected with HIV.[16] However, the Medicaid programs establish restrictive eligibility

criteria, requiring during 1993 that incomes be below $434 per month in most states." Programs funded by the Ryan White CARE Act provide services to people with AIDS and HIV infection with higher income levels, broadening and strengthening the public-sector safety net for financing HIV-related health care. This paper focused on the health insurance continuation programs funded by Tile II of the CARE Act, presenting data on the health insurance benefits covered, medical and financial eligibility criteria for assistance, and the implementation of waiting lists for assistance.

In all states implementing the health insurance continuation program with Tie II funds, the programs cover health insurance premiums, with a few states also covering copayments, coinsurance, and/or deductibles. The study documents that the state Tile II programs have established generous income eligibility standards for assistance provided by the health insurance continuation programs, especially when compared to Medicaid eligibility standards. Hence, the health insurance continuation programs funded by Tile II can provide services to people infected with HIV who have incomes too high to become eligible for Medicaid coverage. The Title II programs strengthen the public-sector safety net for funding the care needed by people with HIV-related illness.

However, if federal funding for Title II programs is not sufficiently increased to keep up with the increasing number of people expected to receive benefits from Title II programs, or if future' federal Medicaid reform allows the states to establish even more restrictive Medicaid eligibility standards, then the Title II programs may not be able to provide services for all eligible people. This could result in the use of waiting lists, reduced services, some other forms of rationing, or the implementation of more restrictive eligibility criteria. If federal funding for Title II programs in the future does

not keep pace with the expected increase in the number of people eligible for Tile II services, then the public-sector safety net for financing HIV-related care will be weakened.

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6. Congressional Research Service, 1993. Medicaid Source Book: Backaround Data and Analysis (A 1993 Update) (Washington, D.C.: U.S. Government Printing Office, 1993). For example, under COBRA the individual pays the full premium, plus 2 percent to administer COBRA, for a total of 102 percent of the premium ("Benefits Planning -- What You Must Know: Interview with Daniel Fortuno, AIDS Benefits Counselors," AIDS Treatment News, issue Number 266, September 20, 1996).

7. Congressional Research Service, 1993. Medicaid Source Book: Backaround Data and Analysis (A 1993 Update) (Washington, D.C.: U.S. Government Printing Office, 1993). For example, under OBRA the individual pays the full premium, plus 60 percent, for a total of 160 percent of the premium ("Benefits Planning -- What You Must Know: Interview with Daniel Fortuno, AIDS Benefits Counselors,' AIDS Treatment News, Issue Number 266, September 20.1996).

a. For a person with HIV illness to become eligible for Medicare requires meeting eligibility criteria for Social Security Disability Insurance (SSDI), induding disability status, sufficient work-related history, and a 29-month waiting period (5 months from disability status for SSDI payment to begin, then 24 additional months for Medicare coverage to begin). Baily, M., Bilheimer, L, Woofridge, J., Langwell, K, and Greenberg, W. "Economic Consequences for Medicaid of Human Immunodeficiency Virus Infection.' Health Care Financing Review (1990 Annual Supplement): 97-I 06.

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11. Centers for Disease Contrd and Prevention HIV/AIDS Surveillance Report, 1995; 7(no.2): I-39. Figure 1: Male adult/adolescent AIDS annual rates per 100,000 population, for cases reported in 1995, United States.

12. Although Alaska and Arkansas repotted that Tie II funds were not used in those states to implement a health insurance continuation program, these benefits were provided by Tie II HIV consortia. Data on the continuation of health insurance coverage were included in the responses from Alaska and Arkansas to the health insurance continuation survey and these data are reported in Tables 3 and 4 of this paper.

13. See note 3.

14. Buchanan, R. "Medicaid Eligibility Policies for People with AIDS.' Social Work In Health Care Vol.23,No.2(1996): 1541.

15. See note 14.

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17. See note 14.

Chapter 6
The Medicaid Home and Community-Based Care Waiver Programs: Providing Services to People with AIDS"

Introduction

The state Medicaid programs can use the home and community-based waiver programs to provide a broad array of noninstitutional services to Medicaid recipients who require, or are likely to require, long term care at the intermediate nursing care level or higher (Miller, 1992). These waiver programs are designed to encourage Medicaid coverage of more appropriate home and community-based care as an alternative to more costly institutional care (Dobson, Moran, and Young, 1992). Section 2176 of the 1981 Omnibus Budget Reconciliation Act gives the Health Care Financing Administration the authority to waive certain federal Medicaid regulations to allow the states to include home and community-based services in their Medicaid coverage, targeted to specific Medicaid recipients such as the elderly or the physically disabled who would otherwise have to be institutionalized (Merzel, Crystal, Sambamoorthi, Karus, and Kurland, 1992; Miller, 1992). The Omnibus Budget Reconciliation Act of 1985 amended Section 2176 to allow AIDS-specific, Medicaid home and community-based waiver programs (Jacobson, Lindsey, and Pascal, 1989). The Technical and Miscellaneous Revenue Act of 1988 extended eligibility for these waiver programs to people with specific diseases (including AIDS) who were not receiving care at a hospital or nursing facility but who did require nursing-facility or

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[a]This research is published in HEALTH CARE FINANCING REVIEW, Vol. 18, No. 4, 1997.

hospital-level care (Cowan and Mitchell, 1995). The Medicaid programs can use either the AIDS-specific waiver program or the original waiver program to provide special services to Medicaid recipients with AIDS due to their disability status (Ellwood, Fanning, and Dodds, 1991; Baily, et al., 1990; Buchanan, 1996).

These home and community-based care waivers give the states flexibility not only in defining the populations to be covered, but also in defining the range of services to be covered (Lindsey, Jacobson, and Pascal, 1990). Among the services allowed are case management, homemaker, home health aide, personal care, adult day care, habilitation, day treatment, partial hospitalization services, respite care, psychosocial rehabilitation, private duty nursing, medical supplies and adaptive equipment, transportation, and home-delivered meals (Merzel, Crystal, Sambamoorthi, Karus, and Kurland, 1992). The waiver programs also allow more generous financial eligibility requirements (Buchanan, 1996). The states may establish income standards for the waiver programs up to 300 percent of the Supplemental Security Income benefit (Congressional Research Services, 1993). One half of the people with AIDS covered by the AIDS-specific home and community-based care waiver in New Jersey was entitled to coverage only due to these more generous waiver eligibility standards (Merzel, Crystal, Sambamoorthi, Karus, and Kurland, 1992).

The objective of this study is to present the results of a survey demonstrating how the state Medic&d programs are using the home and community-based care waiver programs to provide health services to people with AIDS. In addition, by including the waiver programs for the elderly and disabled in the survey, along with the

AIDS-specific waiver program, the study illustrates the specialized services available to other targeted groups of people as well as to people with AIDS.

Methodology

To discover how the states were implementing the home and community-based care waiver programs during 1995, a questionnaire was mailed during June, 1995 to the Medicaid administrators responsible for the waiver programs in each state. Six additional mailings of the questionnaire were sent to the states not responding, with completed surveys received from 49 states and the District of Columbia by September, 1996.[b] The survey responses were summarized into tables, which were mailed back to the Medicaid administrators for verification, corrections, and updates in August, 1996. The verification process was completed during November, 1996. These veriied and updated tables are presented in this research as Tables 6-1 through 6-6.

The questionnaire was divided into three sections: Medicaid Home and Community-Based Care Waiver for the Elderly and Disabled; a separate Medicaid Home and Community-Based Care Waiver for the Disabled; and a separate AIDS-specific Medicaid Home and Community-Based Care Waiver. To facilitate the completion of the questionnaire, each of the three sections included the following list of services, with a request to circle any service covered by that particular waiver program during 1995:[c]

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[b] **The Massachusetts Medicaid program did not complete the survey process.**

[c] **Note that each list of services included "Other (please describe)."**

skilled and private duty nursing
home aerosolized drug therapy
home respite care
day treatment/partial hospitalization
in-home diagnostic testing
home intravenous therapy
home mobility aids/devices
substance abuse services
rehabilitation services
home-delivered meals
HIV support groups
HIV prevention education for families
other (please describe):

homemaker services
adult medical day care
inpatient respite care
durable medical equipment
emergency home response
transportation services
home/environmental modifications
mental health counseling
podiatry services
congregate meals services
child care services
adult social day care

personal care services
live-in attendant
medical social services
hospice care
case managers
benefits advocacy
handyman services
nutritional counseling
dental care
housing referrals
legal services
moving assistance

Each of the three sections of the questionnaire asked the Medicaid administrators to list any services covered by that particular Medicaid Home and Community-Based Care waiver program during 1995 that was "most effective at meeting the health care needs of people with HIV-related illness." Each of the three sections also asked the Medicaid administrators to "estimate the number of Medicaid recipients with HIV-related conditions who received services" from that particular waiver program during 1994. In addition, the section of the questionnaire focusing on the AIDS-specific Home and Community-Based Care Waiver asked the Medicaid administrators to "estimate the number of Medicaid recipients with HIV-related conditions 18 years of age and younger who received services" from that waiver program during 1994. The questionnaire concluded by requesting a copy of the most recent HCFA 372 Repot-t available for the AIDS-specific waiver.[d]

[d] **The HCFA Form 372 is the Annual Report on Home and Community-Based Services Waivers, which includes reports on expenditures and other program data (Lindsey, Jacobson, and Pascal, 1990). The HCFA 372 data returned by most states were incomplete, with many states not returnlng any HCFA 372**

The AIDS-Specific Waiver

As Table 6-1 documents, 15 states implemented an AIDS-specific Medicaid Home and Community-Based Care Waiver Program during 1995, including North Carolina which began its waiver program on November 1, **1995.** In addition to these 15 states, an AIDS/HIV-specific waiver program was approved for the District of Columbia in December, 1996 and Maine expects to implement an AIDS-specific waiver program during 1997. Although not a separate, AIDS-specific waiver, Maryland implements a "targeted case management program" through its regular Medicaid state plan for people who are infected with HIV (see Table 6-i). In addition to the services provided on the questionnaire, Table 6-l presents other HIV-related services covered by a number of states with their AIDS-specific waiver programs. Examples of these other services are: physical therapy, massage services, companion services, stipends to foster families caring for children who are infected with HIV, and nutritional supplements.

Table 6-2 lists the services provided by the AIDS-specific waiver programs that the state Medicaid administrators identified as most beneficial at meeting the care needs of people with AIDS. Among the services mentioned are: personal care, nursing care, case management, home-delivered meals, respite care, counseling, homemaker services, home intravenous therapy, hospice care, nutritional counseling

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data. Due to the possible bias of these data, given the large number of states not reporting data, these HCFA 372 data are not included in this paper. Tables summarizing the limited HCFA 372 data that were reported in the survey are presented in Appendix 2.

Table 6-1
The AIDS-Specific, Medicaid Home and Community-Based Dare Waiver Program:
Services Covered During 1995

	The Home and Community-Based Care Services Covered During 1995:
California	skilled nursing,, homemaker services, home-delivered meals, nutritional/dietary supplements, specialized medical equipment and supplies, non-emergency medical transportation services, home/environmental modifications, psychosocial counseling, attendant care, case managers, nutritional counseling, and Medi-Cal supplement for infants and children in foster care
Colorado	skilled and private duty nursing, homemaker services, adult day care, emergency home response, transportation services, and personal care services
Delaware	in-home respite care, homemaker services, adult medical day care, inpatient respite care, mental health counseling, personal care services, case managers, and nutritional supplement (new service to be added in 1995).
District of Columbia	An AIDS/HIV-specific waiver was approved in December, 1996
Florida	skilled & private duty nursing, home aerosolized drug therapy, in-home respite care, day treatment/partial hospitalization, home intravenous therapy, home mobility aids/devices, substance abuse services, rehabiliion services, home-delivered meals, HIV prevention education for families, homemaker services, adult medical day care, inpatlent respite care, emergency home response, home/environmental modifications, mental health counseling, personal oare services, case managers, handyman services, physical therapy, massage services, companion services, and moving assistanoe (labor) (not as a separate service)
Hawaii	skilled nursing, respite care, medical day health care, emergency alarm response, non-medical transportation services, counseling and training (includes nutritional and substance abuse counseling), personal care services, case managers, moving assistance, home-delivered meals, and supplemental stipend to foster families oaring for children who are HIV infected
Illinois	homemaker services, adult medical day care, emergency home response, home/environmental modifications, personal care services
Iowa	skilled and private duty nursing, in-home respite oare, home-delivered meals, home health aide, homemaker services, mental health counseling, and personal care
Maine	Maine expects to implement an AIDS-specific waiver during, 1997
Maryland	The Medicaid program in Maryland 'does not have a specific waiver for people with AIDS, however, a targeted oase management program is available under the state plan for people who are HIV positive. [Medicaid] recipients who are diagnosed as HIV positive or are less than two years old and born to a woman diagnosed as HIV infsoted are eligible to receive services. A multidisciplinary team assesses the individual and develops a written plan of care that addresses all the recipient's medical, psychological, social, functional, and other needs. The recipient can then elect to receive ongoing case management services to implement the plan of care. The case manager . . [makes] referrals to and arrangements with service providers selected by the recipient and [advises] the recipient about all available services. . . . The HIV Targeted Case Management Program is a totally voluntary, clientdriven program. The recipient participates fully in the development and implementation of the plan of care.
Missouri	skilled and private duty nursing, transportation services, personal care services, diapers, chucks, gloves, and case managers
New Jersey	skilled and private duty nursing, home aerosolized drug therapy, day treatment/partial hospiiixation, in-home diagnostic testing, home intravenous therapy, home mobilii aids/devices, substance abuse services, rehabilitation services, adult medical day care, durable medii equipment, transportation sewioes, mental health counseling, podiatry services, psrsonal care services, medical social services, hospice care, case managers, nutritional counseling, and dental care
New Mexico	skilled and private duty nursing, homemaker services, personal oare services, and case managers ("We would like to add home health aide and adult day health services.?
North Carolina	The AIDS-specific waiver will be implemented on 1 1/1/95 and cover: in-home respite care, home mobility aids/devices, home-delivered meats, homemaker services, adult medical day care, inpatient respite care, emergency home response, home/environmental modifications, Personal care and case managers
Pennsylvania	skilled nursing, in-home respite care (homemaker services), homemaker services, durable medical equipment, child care services (homemaker services), personal care services (homemaker services), and nutritional counseling (case management is a state plan service covered as targeted case management)
South Carolina	skilled and private duty nursing, home-delivered meals, HIV support groups/individual counseling, home/environmental modifications, personal care services, hospice care, case managers, and foster care
Virginia	case management, personal care, skilled nursing services, respite care, and nutritional supplements
Washington	hourly skilled nursing, attendant care, respite care, therapeutic homedeliiered meals, psychosocial services, transportation, nutrition consultation, intermittent nursing services, and adult day health care
Other states (except Massachusetts) responded that they did not have an AIDS-specific Home and Community-Based Dare Waiver program during 1995. The Massachusetts Medicaid program did not complete the questionnaire.	

Table 6-2
The Medicaid Home and Community-Based Care Waiver Program for People with AIDS:
Beneficiaries with HIV-Related Conditions and Effective Services for People with HIV-Related Conditions

	Effective Home & Community-Based Care Waiver Services for People with HIV-Related Illness	Number of Medicaid Recipients with HIV Illness Receiving Services from Waiver Program for People with AIDS
California	all AIDS/HIV waiver services are necessary and helpful	adults: 2500 people (1994) children 18 years and younger: 300 (1994)
Colorado	personal care	adults: 125 people (1995) children 18 years and younger: 3 (1995)
Delaware	"All services [covered in the AIDS waiver] . . . in addition to regular Medicaid covered services."	adults: 86 people (1994) children 18 years and younger: 0 (1994)
District of Columbia	An AIDS/HIV-specific waiver was approved in December, 1996	Not applicable
Florida	"All AIDS waiver services are medically necessary."	adults: 6,000+ people (1994) children 18 yrs. & younger: data not available
Hawaii	personal care services, case management services, home-delivered meals, and counseling and training services	adults: 104 people (1994) children 18 years and younger: 0 (1994)
Illinois	all waiver-covered services are beneficial to people with AIDS	adults: 1,368 people (1994) adults: 2,292 people (1995) children 18 yrs. & younger: data not available
Iowa	Skilled and private duty nursing, in-home respite care, in-patient respite care, counseling, home health aide services, homemaker services, and home-delivered meals	adults: 19 people (1994) children 18 years and younger: 0 (1994)
Maine	Maine expects to implement an AIDS-specific waiver during 1997	
Maryland	Maryland does not have an AIDS-specific, Medicaid Home and Community-Based Waiver, but implements the program "HIV Targeted Case Management Services". (See Table 1) This program served 760 people during 1994.	
Missouri	skilled and private duty nursing	adults: 200 people (1994) children 18 years and younger: 10 (1994)
New Jersey	case management, private-duty nursing, home I.V. therapy, personal care services and hospice care	adults: 1,428 people (1994) children 18 years and younger: *
	*"We have served 318 children under 20 [years of age] from 3/87 to 12/94. No stats. on the number served in 1994."	
New Mexico	private duty nursing and homemaker/personal care services. "We would like to add home health aide and adult day health services.	adults: 70 people (1995) children 18 years and younger: 1 (1995)
North Carolina	North Carolina implemented an AIDS-specific, Medicaid Home and Community-Based Waiver effective 11/1/95	
Pennsylvania	homemaker services, nutritional consultations, and nutritional supplements	adults: 173 people (1993/1994) children 18 years and younger: *
	*Not applicable because "services are provided under the Early Periodic Screening and Diagnosis Program."	
South Carolina	private duty nursing, personal care aide services, and counseling	adults: 594 people (1994) children 18 years and younger: 6 (1994)
Virginia	data not available	data not available
Washington	"The waiver services most effective are home health aides and personal care attendants assisting with 4 to 8 hours per day or to supplement care in residential settings. Waiver services are in addition to the usual state Medicaid home health services."	adults: 54 people (1995) children 18 years and younger: 1 child (1995)
All other states (except Massachusetts) responded that they did not havo an AIDS-specific Home and Community-Based Care Waiver program during 1995. The Massachusetts Medicaid program did not complete the questionnaire.		

and supplements, and personal care attendants. Table 6-2 also presents the number of adults and children that received services from the AIDS-specific Home and Community-Based Care Waiver Programs during 1994.

The Elderly and Disabled Waiver

As Table 6-3 illustrates, each Medicaid program, except the District of Columbia, provided services to eligible groups with the Medicaid Home and Community-Based Care Waiver Program for the Elderly and Disabled during 1995. (The Massachusetts Medicaid program did not complete the survey process.) In addition to the services listed on the questionnaire, a number of states also covered other home and community-based services. Examples of these other services are: chore services; habiliition services; alternative care facilities; elderly foster care; laundry services; assisted-living services; respiratory therapy; psychological consultation for family members and other caregivers; speech, physical, and occupational therapies; training of family caregivers; and specialized living facilities.

Case management has been identified as one of the most important waiver services needed by people with AIDS (Merzel, Crystal, Sambamoorthi, Karus, and Kurland, 1992). When the Medicaid administrators were asked in the survey to identify services covered by the waiver program for the elderly and disabled in their state that were most effective at meeting the care needs of people with AIDS, case management services were consistently mentioned, as Table 6-4 documents. Other services that were listed in the survey responses as most effective at meeting HIV-related care needs are: personal care, homemaker services, in-home and inpatient respite care,

Table 6-3
The Medicaid Home and Community-Based Care Waiver Program for the Elderly and Disabled: Services Covered During 1995

	The Home and Community-Based Care Services Covered During 1995:
Alabama	in-home raspite care (skilled and unskilled), homemaker services, adult social day care, personal care services, and case managers
Jaska	skilled and private duty nursing, in-home respite care, home-delivered meals, snore services, emergency home response, transportation services, home/environmental modifications, congregate meal services, adult social day care, case managers, and specialized medical equipment and supplies. In addition to these services, habilii and intensive active therapies are available for the disabled.
Arizona	skilled and private duty nursing, in-home raspite care, home intravenous therapy, home mobility aids/devices, substance abuse services, rehabilii services, home-delivered meals, homemaker services, adult day care, inpatient raspite care, durable medical equipment, emergency home response, transportation services, home/environmental modifications, mental health counselina, personal care services, liin attendant, hospice care, case managers, handyman services, and nutritional counseling
Arkansas	in-home respite care, home-delivered meals, homemaker services, adult mediil day care, inpatient respite care, emergency home response, adult social day cars, and chore services (e.g.., errands, household tasks, yard maintenance)
California	The California Medicaid program provides home and community-based care waiver services to people with AIDS through the AIDS-specific waiver
Colorado	homemaker services, adult day care, emergency home response, transportation services, home/environmental modii, personal care services, and alternative care facilities
Connecticut	skilled and private duty nursing, in-home respite care, rehabilitation services, home-delivered meals, homemaker services, adult medical day care, inpatient respite care, emergency home response, transportation services, mental health counseling, adult social day care, case managers (including benefits advocacy), chore services, elderly foster care, horns health aide, and laundry services
Delaware	in-home respite care, homemaker services, adult medical day care, inpatient respite care, emergency home response, adult social day care, personal care services, and case managers
District of Columbia	no Medicaid Home 8 Community-Based Care Waiver for the Elderly and Disabled during 1995.
Florida	in-home respite care, home mobility aids/devices, home-delivered meals, homemaker services, adult medical day care, emergency home response, mental health counseling, adult social day care, personal care services, case managers, benefits advocacy, handyman services, and nutritional counseling
Georgia	skilled and private duty nursing, in-home respite care, rehabilitation services, home-delivered meals, homemaker services, inpatient respite care, emergency home response, personal care services, mediil social services, case managers, and atternative liing services
Hawaii	skilled nursing, respite care, home-delivered meals (including congregate meals), homemaker services, emergency alarm response, non-medical transportation services, personal care services, nutritional counseling, moving assistance, homenlaintenanca, environmental modii. adult day health care, and case managers
Idaho	personal care services and case managers ("Medicaid clients under age 21 may be eligible for other services through Early and Periodic Screening, Diagnosis, and Treatment.")
Illinois	homemaker services, adult medical day care, emergency home response, home/environmental modifications, personal care services, and case managers
Indiana	in-home respite care, home mobility aids/devices, home-delivered meals, homemaker services, inpatient respite care, emergency home response, home/environmental modifications, adult day care, attendant care services, and case managers
Iowa	skilled and private duty nursing, in-horns raspite care, home mobility aids/devices, home-delivered meals, homemaker services, inpatient respite care, emergency horns respons~, transportation services, home/environmental modifications, mental health outreach, adult social day care, personal care services, handyman/chore services, and home health aid
Kansas	in-home respite dare, homemaker services, adult medical day care, inpatient respite care, emergency home response, transportation services, adult social day care, personal care services, and case managers
Kentucky	in-home respite care, homemaker services, adult mediil day care, home/environmental modii, personal care services, and case managers
Louisiana	emergency home response, home/environmental modifications, personal care services, and case managers
Maine	For the Elderly: skilled and private duty nursing, rehabilitation services, homemaker services, adult medical day care, emergency home response, transportation services, mental health counseling, personal care services, liin attendant, medical social services, and case managers
Maryland	Senior Assisted Housing Waiver: home/environmental modifications, adult social day care, behavior consultation, e n v i r o n m e n t a l - , assistive equipment and case managers (not a waiver service, but provided as part of the duties of administering the waiver); also homemaker services, personal care services, preparation and serving of meals, and medication assistance are provided as part of the assisted living services package.
Massachusetts	The data from Massachusetts is in the verification process
Michigan	private duty nursing, in-horns rewite care, dav, treatment. home-delivered meals. homemakerservims, inpatient respite care (foster care), durable medical equipment, emergency home response, transportation services, home/environmental modifications, adult social day care, personal care supervision,. case managers, chore services, training, medical sup&ii, and counseling (not just mental health)
Minnesota	skilled and private duty nursing, in-home raspite care, home-delivered meals, homemaker services, inpatient raspite care, emergency home response, transportation services, home/environmental modifications, adult social day care, personal care services, case managers, and special&d foster home
Mississippi	home-delivered meals, homemaker services, adult medical day care, inpatient respite care, case managers, and extended home health care coverage (Le.. in addii to the allowed visits under the state plan)
Missouri	in-home raspite care, homemaker services, case managers, and handyman services (these services are available only to recipients who are 65 years or older)

Table 6-3
The Medicaid Home and Community-Based Care Waiver Program for the Elderly and Disabled:
Services Covered During 1995

	The Home and Community-Based Care Services Covered During 1995:
.ontana	skilled and private duty nursing,' in-home respite care, home mobility aids/devices,* home-delivered meals, homemaker services, inpatient respite care, emergency home response, transportation services (social only), home/environmental modii, congregate meal services, adult social day care, personal care services, case managers, nutritional counseling, moving assistance, habilii services, respiratory therapy, and psychological consultation (for family members or other caregivers)
	*covered under both the state plan and the waiver program, but the waiver service is defined differently. "For e.g., state plan personal care does not allow for supervision and homemaker tasks, ... [but] are allowed under the HCBS waiver."
Nebraska	in-home respite care, homemaker services, adult medical day care, out-of-home respite care, transportation services, and handyman services
Nevada	in-home respite care, home-delivered meals, homemaker services, adult social day care, personal care services (covered in state plan too), medical social services, and case managers (the state plan covers many additional home and communtity-based care services)
New Hampshire	skilled nursing, home aerosolized drug therapy, in-home diagnostic testing, home intravenous therapy, home mobility aids/devices, rehabilitation services, home-delivered meals, homemaker services, adult medical day care, inpatient respite care, durable medical equipment, emergency home response, transportation services, home/environmental modifications, mental health counseling, podiatry services, congregate meal services, and case managers
New Jersey	skilled nursing, in-home respite care, homemaker services, adult medical day care, inpatient respite care, transportation services, adult social day care, medical social services, hospice care, case managers, and nutritional counseling
New Mexico	skilled and private duty nursing, in-home respite care, homemaker services, personal care services, and case managers; Effective 7/1/95 "we intend to amend the Disabled/Elderly waiver to include adult day health care, assisted living, personal services, environmental modifications, emergency response, and P.T., O.T., and speech therapy
New York	in-home respite care, home-delivered meals, inpatient respite care, emergency home response, transportation services (for wcial day care). adult social day can?, home/environmental modifications, medical social services, case managers (part of package of services), nutritional counseling, and moving assistance
North Carolina	in-home respite care, home mobility aids/devices, home-delivered meals, homemaker services, adult medical day care, inpatient respite care, emergency home response, home/environmental modifications, personal care services, and case managers
North Dakota	institutional and in-home respite care, homemaker services, adult social day care, personal care services, chore services, case managers, specialized equipment, environmental modification, non-medical transportation, training of family caregivers, and home health aide
	North Dakota has a Service Payments for the Elderly and Disabled (SPED) Program and an Expanded SPED Program which arefundedbystateandcounlyrevenues. Several people with AIDS receive in-home services from these programs.
hio	in-home respite care, home-delivered meals, homemaker services, home/environmental modifications, personal care services, and case managers
Oklahoma	skilled and private duty nursing, in-home respite care, home-delivered meals, homemaker services, inpatient respite care, durable medical equipment, home/environmental modifications, adult social day care, personal care services, and case managers
Oregon	home care services, live-in attendant (including in-home respite care), home/environmental modificatioon_home-delivered meals, residential care faciii, assisted-living facilii. adult foster homes, and specialized living facilii
Pennsylvania	skilled nursing, in-home respite care, home mobility aids/devices, rehabilitation services, home-delivered meals, homemaker services, adult medical day care, inpatient respite care, durable medical equipment, emergency home response, transportation services, home/environmental modifications, mental health counseling, adult social day care, personal care services, case managers, handyman services, and nutritional counseling
Rhode Island	homemaker services, emergency home response, personal care services, and home/environmental modifications
South Carolina	home-delivered meals, adult medical day care, inpatient respite care, home/environmental modifications, personal care services, medical social services, and case managers
South Dakota	skilled and private duty nursing, homemaker services, and adult social day care
Tennessee	home-delivered meals, homemaker services, home/environmental modifications, personal care services, and case managers
Texas	skilled and private duty nursing, in-home respite care, home mobility aids/devices, rehabilitation services, durable medical equipment, emergency home response, home/environmental modifications, and personal care services
Utah	in-home respite care, home-delivered meals, homemaker services, inpatient respite care, emergency home response, transportation services, adult social day care, and case managers
Vermont	in-home respite care, inpatient respite care, adult social day care, personal care services, and case managers
Virginia	The Virginia Medicaid program provides home and community-based care waiver services to people with AIDS through the AIDS-specific waiver
Washington	skilled nursing, home-delivered meals, emergency home response, transportation services, home health aide, night support, client training, assisted living, home/environmental modifications, adult social day care, and personal care services
West Virginia	homemaker services, transportation services, personal care services, case managers, and chore services
Visconsin	in-home respite care, home mobility aids/devices, rehabilitation services, home-delivered meals, homemaker services, adult medical day care, inpatient respite care, durable medical equipment, emergency home response, transportation services, home/environmental modifications, mental health counseling, adult day care, personal care services, live-in attendant, case managers, benefits advocacy, chore services and nutritional counseling
Wyoming	personal care, respite care, adult day care, home-delivered meals, PERS, and non-medical transportation

attendant care, hospice care, home-delivered meals, and unlimited prescription drugs.' (See Table 6-4.) As Table 6-4 also illustrates, the Medicaid Home and Community-Based Care Waiver Programs for the Elderly and Disabled provided services to Medicaid recipients with HIV-related conditions in a number of states.

The Disabled Waiver

Most states did not have a separate Medicaid Home and Community-Based Care Waiver Program for the Disabled, as Table 6-5 demonstrates, but often combined this coverage with the waiver program for the elderly. Table 6-5 presetits the services covered by the states implementing a separate waiver program for the disabled. However, many of these separate waiver programs for the disabled are targeted at specific groups of people with disabilities and are not available to most people with AIDS. For example, the Medicaid Home and Community-Based Care Waiver Program for the disabled in Connecticut is targeted to people with mental retardation. According to the survey response, Connecticut is developing a new waiver for people with physical disabilities and another new waiver for people with an acquired brain injury. The separate waiver program for the disabled in Hawaii is targeted to the developmentally disabled and other Hawaiians with disabilities are served through the waiver programs for the elderly and disabled. (Hawaii also implements the AIDS-specific waiver.) Similarly, the waiver program for the disabled in Louisiana is targeted to the developmentally disabled. New Jersey has several waiver programs for the

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• The state Medicaid programs may impose utilization limits on the prescription drugs covered by the regular state Medicaid plan (Buchanan and Smith, 1994).

Table 6-4

The Medicaid Home and Community-Based Care Waiver Program for the ❑ derly and Disabled: Beneficiaries with HIV-Related Conditions and Effective Services for People with HIV-Related Conditions

	Effective Home & Community-Based Care Waiver Services for People with HIV-Related Illness	Number of Medicaid Recipients with HIV Illness Receiving Services from Waiver Program for Elderly and Disabled
Alabama	personal care, homemaker services, case manager, and respite care	diagnosis-specific data not available
Alaska	"No AIDS-specific waiver. However, services available through our present waivers can meet the needs of HIV-related individuals."	1 person
Arizona	respite care, hospice care, case manager, attendant/personal care, and home health services (nursing and aide)	data not available
Arkansas	"Any of these [waiver] services could be used by AIDS recipients, if they meet the criteria."	data not available
California	California has an AIDS-specific Home & Community-Based Services waiver	2,500 adults and 300 children (18 years or younger) received services during 1994 from the AIDS-specific waiver
Colorado	"We have our own HCBS waiver for AIDS/HIV - but they may still access the elderly waiver if they want."	data not available
Connecticut	all waiver services are available if the person is determined eligible for the waiver program	data not available
Delaware	"All [waiver-covered services in Delaware] in addition to regular Medicaid-covered services."	data not available
District of Columbia	no Medicaid Home & Community-Based Care Waiver for the Elderly and Disabled during 1995	not applicable
Florida	Florida has an AIDS-specific Home & Community-Based Services waiver	data not available
Georgia	"AIDS clients may use the program if they meet the eligibility criteria."	data not available
Hawaii	Hawaii has an HIV/AIDS-specific Home & Community-Based Services waiver	104 people with HIV/AIDS received services during 1995-1996 in the HIV/AIDS waiver program
Idaho	"HCBS waiver services are very limited [in Idaho]."	"We estimate that a small number of HCBS clients have HIV-related conditions."
Illinois	all the services covered by the waiver program are effective at meeting the care needs of people with HIV-related illness	data not available
Indiana	case management, homemaker services, and attendant care	13 people with HIV-related illness during FY 1996
Iowa	Skilled and private duty nursing, in-home respite care, in-patient respite care, counseling, home health aide services, homemaker services, and home-delivered meals	19 people with HIV-related illness during 1994
Kansas	personal care services	data not available
Kentucky	The services provided through the waiver program are available to all eligible people; HIV-specific data is not collected	HIV-specific data is not collected
Louisiana	not available	data not available
Maine	"The waivers for the elderly and disabled are not "targeted" to the HIV-related illness."	The Elderly waiver provided services to no one with HIV-related illness during 1995.
Maryland	data not available if Senior Assisted Housing Waiver has provided services to people with HIV-related illness.	not applicable
Massachusetts	The data from Massachusetts is in the verification process	
Michigan	"Use all services as any other waiver client. No one or two specific services stand out."	"Due to confidentiality issues in the State, we don't keep this specific data."
Minnesota	specialized foster home/hospice	20 people with HIV-related illness
Mississippi	"Care plans are individualized with the appropriate waiver-covered services provided."	data not available
Missouri	Missouri has an AIDS-specific Home & Community-Based Services waiver	200 people received services from the AIDS-specific waiver program

Table 6-I

The Medicaid Home and Community-Based Care Waiver Program for the ❑ derly and Disabled: Beneficiaries with HN-Related Conditions and Effective Services for People with HIV-Related Conditions

	Effective Home & Community-Based Care Waiver Services for People with HIV-Related Illness	Number of Medicaid Recipients with HIV Illness Receiving Services from Waiver Program for Elderly and Disabled
Montana	personal care, private duty nursing, home-delivered meals, and respite care*	2 people with HIV-related illness during 1994
	*"We have excellent benefits under our state plan so many individuals with AIDS do not need to be enrolled in the waiver program to receive the services they need. We are adding ... special child care for children with AIDS, to allow us to provide in-home day care to the one child currently enrolled."	
Nebraska	"Needs not tracked by type of disability."	5 people with HIV-related illness
Nevada	homemaker services, personal care services, and case management (which includes medical social services)	0 people with HIV-related illness during 1994 or 1995
New Hampshire	none mentioned	20-25 people with HIV-related illness
New Jersey	New Jersey has an AIDS-specific Home & Community-Based Services waiver	not applicable
New Mexico	"The Disabled/Elderly [waiver program] is not serving anyone with HIV-related illness [during 1995]."	0 people with HIV-related illness during 1995
New York	no services mentioned	874 people with HIV-related illness during calendar year 1994
North Carolina	"People with HIV-related illness may be served under our Home and Community-based waiver program."	data not available
North Dakota	"Most services are delivered to those persons eligible for nursing facilii level of care. All [waiver services covered in North Dakota] would be effective if those eligible have an HIV-related illness."	"We do not separate this data. If a person is nursing facility eligible, we do not look at their diagnosis."
	North Dakota has a Service Payments for the Elderly and Disabled (SPED) Program and an Expanded SPED Program w are funded by state and county revenues. Several people with AIDS receive in-home services from these p&ram8.	
Ohio	home-delivered meals, homemaker services, and personal care	"Exaot number not known – less than 150 people [with HIV-related illness].
Oklahoma	not applicable	0 people with HIV-related illness
Oregon	HIV-related clients are not identified as a separate service category. HIV clients (even if known) are assimilated into all care settings. In most cases HIV-diagnosed clients are not known, unless self identified."	
Pennsylvania	Pennsylvania has an AIDS-specific Home & Community-Based Services waiver	about 200 people are served aaoh year under the AIDS-specific waiver
Rhode Island	Serostim drug therapy - a growth hormone for persons with AIDS-wasting syndrome	30 people with HIV-related illness a year
South Carolina	South Carolina has an AIDS-specific Home & Community-Based Services waiver	not applicable (0 people with HIV-related illness in the year ending 9/30/94)
South Dakota	not applicable at this time	0 people with HIV-related illness
Tennessee	personal care services, homemaker services, home-delivered meals, case management, and home/environmental modifications	1 person with HIV-related illness during 1994
Texas	Medicaid health insurance, unlimited prescription drugs, skilled nursing services, and personal care services	data not available
Utah	not applicable	0 people with HIV-related illness
Vermont	unknown	unknown
Virginia	The Virginia Medicaid program provides home and community-based care waiver services to people with AIDS through the AIDS-specific waiver	
Washington	all waiver services are effective	"This data is not collected."
West Virginia	insufficent data to respond	4 people with HIV-related illness during 1996
Wisconsin	personal care, live-in attendant, homemaker services, adaptive aids, horns-delivered meals, and respite care	"We do not collect this data."
Wyoming	"[People with] HIV are not treated as a group, only as part of the HCBS population meeting established eligibility guidelines.'	'Unknown unless specifically identified."

Table 6-5
The Medicaid Home and Community-Based Care Waiver Program for the Disabled:
Services Covered During 1995

	The Home and Community-Based Care Services Covered During 1995:
Alabama	in-home respite care, assistive technology, emergency home response, home/environmental modifications, personal care services, case managers, and medical supplies ("up to $150 per month for items not covered by the regular Medicaid state plan under durable medical equipment")
Alaska	skilled and private duty nursing, in-home respite care, home-delivered meals, chore services, emergency home response, transportation services, home/environmental modifications, congregate meal services, adult social day care, case managers, habilitation, intensive active therapy, and specialized medical equipment and supplies
Arkansas	home/environmental modifications, adult social day care, medical social services, case managers, employment services crisis abatement (temporary placement in a facility when "recipient cannot be dealt with or is not safe in current environment"), and habilitation ("teach skills to manage in the world, ADL, money management")
California	California has an AIDS-specific Home & Community-Based Services waiver
Connecticut	"Connecticut has a separate Medicaid Home and Community-Based Waiver for people with mental retardation and is developing two new waivers. The first will cover personal assistance services to people with physical disabilities. The second will provide a wide range of services to people with an acquired brain injury."
Florida	in-home respite care, home mobility aids/devices, home-delivered meals, homemaker services, adult medical day care, emergency home response, mental health counseling, adult social day care, personal care services, case managers, benefits advocacy, handyman services, and nutritional counseling
Georgia	For severely disabled: skilled and private duty nursing, home mobility aids/devices, homemaker services, durable medical equipment, emergency home response, transportation services, home/environmental modifications, mental health counseling, personal care services, and case managers
Hawaii	Hawaii has a separate Medicaid Home and Community-Based Waiver for the Developmentally Disabled. Other persons with disabilities are served through combined programs for the elderly/disabled: (1) Nursing Homes Without Walls or (2) Residential Alternatives Community Care Program
Illinois	homemaker services, adult medical day care, emergency home response, home/environmental modifications, personal care services, and case managers
Iowa	in-home respite care, homemaker services, inpatient respite care, adult social day care, personal care services, skilled nursing, and home health aide services
Louisiana	For the developmentally disabled: in-home respite care, home mobility aids/devices, inpatient respite care, emergency home response, home/environmental modifications, personal care services, case managers, and habilitation services (including residential, pre-vocational, supported employment, and day habilitation)
Maine	personal care services and case managers
Michigan	Michigan does not have a separate Medicaid Home and Community-Based Waiver for the Disabled
Minnesota	skilled and private duty nursing, in-home respite care, home-delivered meals, homemaker services, inpatient respite care, emergency home response, transportation services, home/environmental modifications, adult social day care, personal care services, case managers, and specialized foster home
Mississippi	personal care services and case managers ("Recipients must be severely orthopedically or neurologically impaired, with some rehabilitation potential.")
Nevada	homemaker services, medical social services, and case managers (the state plan covers many additional home and community-based care services)
New Jersey	skilled and private duty nursing, home aerosolized drug therapy, in-home respite care, day treatment/partial hospitalization, in-home diagnostic testing, home intravenous therapy, home mobility aids/devices, substance abuse services, rehabilitation services, adult medical day care, inpatient respite care, durable medical equipment, transportation services, home/environmental modifications, mental health counseling, podiatry services, personal care services, medical social services, hospice care, case mangers, nutritional counseling, and dental care*
	*New Jersey has several waivers for the disabled and the services vary according to the specific waiver; these services are provided in at least one of these waivers.
Pennsylvania	skilled nursing, in-home respite care, home mobility aids/devices, rehabilitation services, durable medical equipment, emergency home response, transportation services, home/environmental modifications, personal care services, live-in attendant, case managers, benefits advocacy, handyman services, and housing referrals
South Dakota	in-home respite care, home mobility aids/devices, inpatient respite care, transportation services, case managers (including housing referrals), benefits advocacy, nutritional counseling, and only those dental services not covered by the regular Medicaid program
Virginia	The Virginia Medicaid program provides home and community-based care waiver services to people with AIDS through the AIDS-specific waiver
All other states (except Massachusetts) and the District of Columbia responded that they did not have a separate Home and Community-Based Care Waiver program for the disabled during 1995. A number of these states noted that waiver services for the disabled are combined with the waiver Program for the elderly. The Massachusetts Medicaid program did not complete the questionnaire.	

disabled and also implements the AIDS-specific waiver. The Medicaid waiver program for the disabled in Mississippi is only for the otthopedically or neurologically impaired who have some rehabilitation potential.

Table 6-6 lists the services provided by the waiver programs for the disabled that the state Medicaid administrators identified as most effective at meeting the health care needs of people with AIDS. Among the services mentioned are: personal care, assistive technologies, emergency response, case managers, respite care, homemaker services, home-delivered meals, and medical social services. Table 6-6 also illustrates that a few states provided services to Medicaid recipients with HIV-related conditions with the separate Medicaid Home and Community-Based Care Waiver Programs for the Disabled.

Summary and Conclusions

The Medicaid Home and Community-Based Care Waiver programs allow the states considerable flexibility in defining the groups of people to be served and the range of services to provide (Lindsey, Jacobson, and Pascal, 1990). These waivers allow the states to implement innovative programs to provide long term care to people with AIDS. Given their disability status, people with AIDS who meet the more generous eligibility standards established for these waiver programs may receive services from the Medicaid Home and Community-Based Care waiver programs for the Elderly and Disabled or from a separate waiver for the Disabled (although these waiver programs for the disabled are limited in many states to the developmentally disabled). In addition, 15 states and the District of Columbia (implemented in

Table 6-6
The Mediiid Home and Community-Based Care Waiver Program for the Dii:
Beneficiaries with HIV-Related Condii and Effective **Services** for People with HIV-Related Condii

	Effective Home 8 Community-Based Care Waiver Services for People with HIV-Related Illness	Number of Medicaid Recipients with HIV Illness Receiving Services from Waiver Program for Disabled
Alabama	personal care, mediil supplies, assistive technobgy, emergency response system, environmental modifications, case managers and respite care	diagnosis-specific data not available
Alaska	specialized medical equipment and supplies	1 person with HIV-related illness during 1995
Arkansas	"Any HIV recipient could benefit from any of these [waiver covered] services if the recipient met the criteria of the waiver."	data not available
California	Caliiomia has an AIDS-specific Home & Community-Based. Care waiver	2,500 adults and 300 children (18 years or younger) received services during 1994 from the AIDS-specific waiver
Connecticut	"All waiver services are available if the person is eligible."	data not available
Florida	Florida has an AIDS-specific Home & Community-Based Care waiver	
Georgia	not available/not applicable	no person with HIV-related illness receiving these waiver services
Hawaii	Hawaii does not have a separate Medii Home and Community-Based Waiver for the Disabled, only for the developmentally disabled	
Illinois	all the services covered by the waiver program are effective at meeting the care needs of people with HIV-related illness	data not available
Iowa	Skilled and private duty nursing, in-home respite care, in-patient respite care, counseling, home health aide services, homemaker services, and home-delivered meals	19 people with HIV-related illness received these waiver services in 1994
Louisiana	not applicable	no person with HIV-related illness receiving these waiver services
Maine	personal care services	2 people with HIV-related illness during 1995
Michigan	Michigan does not have a separate Medicaid Home and Community-Based Waiver for the Disabled	
Minnesota	specialized foster home/hospice	20 people with HIV-related illness
Mississippi	"HIV as a lone diagnosis would not qualify an individual for this particular waiver."	
Nevada	homemaker services, case management, and medical social services	1 person with HIV-related illness during 1995
New Jersey	"Persons with HIV-related illness are served under a specific waiver - AIDS Community Care Alternatives Program (ACCAP)"	
Pennsylvania	Pennsylvania has an AIDS-specific Home & Community-Based Services waiver	
South Dakota	not applicable at this time	no person with HIV-related illness receiving these waiver services
Virginia	The Virginia Medicaid program provides home and community-based care waiver services to people with AIDS through the AIDS-specific waiver	
All other states (except Massachusetts) and the District of Columbia responded that they did not have a separate Home and Community-Based Care Waiver program for the disabled during 1995. A number of these states noted that waiver services for the disabled are combined with the waiver program for the elderly. The Massachusetts Medicaid program did not complete the questionnaire.		

December, 1996) have established AIDS-specific Medicaid Home and Community-Based Care waiver programs and Maine expects to implement this AIDS-specific waiver during 1997.

A study of the AIDS-specific waiver in Florida found that people receiving services from this program were generally satisfied with the range and availability of services provided (Cowart and Mitchell, 1995). Case management services are advocated as critical to the care of people with AIDS, with the role of the case manager extending beyond the coordination of health services to include helping people with AIDS cope with their social and emotional needs (Merzel, Crystal, Sambamoorthi, Karus, and Kurland, 1992). As Tables 6-1, 6-3, and 6-5 demonstrate, the Medicaid Home and Community-Based Care waiver programs for people with AIDS, the Elderly and Disabled, and for the Disabled offer case management services in most states. Case management was identified by Medicaid administrators in the survey conducted for this research as among the most effective waiver services provided to people with AIDS. Other services provided by these waiver programs that the Medicaid administrators identified as most effective at meeting the care needs of people with AIDS are: personal care, homemaker services, assistive technologies, emergency response, medical social services, in-home and inpatient respite care, counseling, home intravenous therapy, nutritional counseling and supplements, attendant care, hospice care, home-delivered meals, and unlimited prescription drug coverage. (See Tables 6-2, 6-4, and 6-6.) State Medicaid programs not administering the AIDS-specific waiver program can include these services in their waiver programs

for the elderly and disabled. Since people with AIDS are typically eligible for these waiver programs due to their disability status, even states without the AIDS-specific waiver can then offer Medicaid recipients with AIDS a broad range of needed home care and community-based services.

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Chapter 7
State-Funded Medical Assistance Programs: Sources of Health Coverage for People with HIV Illness[a]

Introduction

Public programs, primarily Medicaid, have become the primary payers for the health services provided to people with HIV disease, covering the care of 53 percent of people infected with HIV and 62 percent of people with HIV who have progressed to AIDS.' State governments spent $401.9 million of state-only funds (excluding Medicaid) on AIDS-related patient care during 1992, an increase of 22 percent over spending for this care during 1991.[2] In spite of this public spending, however, 31 percent of asymptomatic people infected with HIV, 21 percent of symptomatic people infected with HIV (but without AIDS), and 12 percent of people with AIDS lack any public or private health insurance coverage.[3]

An survey of state Medicaid officials working with Medicaid eligibility policies conducted during 1993 found that a number of states implement medical assistance programs (MAPs) funded only with state and/or local government (non-Medicaid) funds.[4] A review of the literature was unable to discover any published papers that describe these state-funded MAPs. The objective of this research is to describe these state-funded MAPs and to discuss how these programs can be used to provide health services to people infected with HIV who lack other coverage.

The Study Methodology

Because the literature contains no discussion or description of these state-funded MAPs, a two-step survey process was used to identify states that implement

[a]This research is under publication review.

these programs. The first step was the identification of states implementing state-funded MAPs and the second step was a survey of the administrators of these programs. The first step of the process involved a new survey of Medicaid administrators who work with Medicaid eligibility policies to identify states implementing state-funded MAPs. These state Medicaid eligibility officials were surveyed because they are in the position to know of other state health programs for low-income people given that Medicaid is a health program for the poor. In addition, Medicaid eligibility is often coordinated with other public programs. The questionnaire asked these Medicaid eligibility officials if their state implemented "a medical assistance 'program (MAP) to pay for the health care provided to the medically indigent (separate from Medicaid) that is 100 percent funded by state and/or local governments during 1995? If their state implemented a MAP, the questionnaire asked the Medicaid administrator to provide the contact person and mailing address for this indigent care program. The Medicaid survey process began in June, 1995, with three additionai mailings sent to the states not returning a questionnaire. When the survey was completed in June, 1996, eligibility administrators 47 Medicaid programs (including the District of Columbia) had returned questionnaires.[b]

Based on the results of the survey of Medicaid eligibility officials, 27 states were identified as possibly having state-funded MAPs. A state-funded MAP questionnaire was developed, which began with "Does your state have a medical assistance program (MAP) for low-income people **(separate from Medicaid)** that is 100 percent funded by state and/or local governments during 1997?" The questionnaire included

[b]Massachusetts, Nevada, Oklahoma, and Virginia did not participate in the survey.

three sections: MAP eligibility policies, MAP covered health services, and MAP payment levels for care.

The MAP survey process began in March,. 1997. Three additional mailings of the questionnaires were sent to the states not responding, with questionnaires returned by 22 states as of November, 1997.[c] Of these 22 states, seven states reported that they did not have a MAP for low-income people that is 100 percent funded by state and/or local governments during 1997.[d] The responses from the states reporting the implementation of state-funded MAPs are summarized into five tables that are presented in this research.

MAP Eligibility Policies

The questionnaire asked the MAP administrators to provide medical and financial eligibility policies that were implemented for the state-funded MAPs during 1997. As Table 7-1 illustrates, these eligibility criteria for MAP benefits vary from state to state. Typically, however, the financial eligibility criteria are restrictive, with most states establishing low income limits. The Delaware MAP is an exception, establishing relatively high income limits. However, this MAP in Delaware is restricted to people with a diagnosis of end stage renal disease, recipients of a kidney transplant, or to dialysis patients.

The survey asked the MAP administrators if the financial eligibility process included a spend down provision, defined on the questionnaire as "allowing the

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[c]Responses were not received from the District of Columbia, Idaho, New York, Pennsylvania, and Rhode Island.

[d]Indiana, Louisiana, North Carolina, North Dakota, Texas, Vermont, and West Virginia responded to the survey that they did not implement a MAP for low-income people that is 100 percent funded by state and/or local governments during 1997.

Table 7-I
State-Funded Medical Assistance Programs (MAPs) for Low-Income People:
Eligibility Policies During 1997

	Medical Eligibility Requirements for MAP in 1997:	To be Financially Eligible for MAP, Gross Monthly Income during 1997 Cannot Exceed: 1-Person Household	4-Person Household	Do MAP Eligibility Determination Procedures Include Spend Down?	Compared to 1995, Financial Eligibility Criteria for MAP in 1997 Became:	The Length of Time for the MAP Eligibility Process in 1996:	Was There a Waiting List for MAP Benefits during 1996?	Estimates of the Percentage of MAP Beneficiaries with HIV in 1996:
Alaska	yes*	$300/month	$600/month	no	remain the same	< 30 days	no	"probably close to 0"
	*"Immediate need for in-patient hospital, nursing home, related transportation, or drugs and/or physician visits for cancer patients receiving chemotherapy, people who are terminally ill, and people who have diabetic seizures, or hypertension, or chronic mental illness."							
Arizona	none	$266/month	$446/month	yes	remain the same	30 days	no	1%
California	The MAP is administered by counties and MAP eligibility policies are determined at the county level.							
Colorado	emergency care, serious threat, and other medical care	(sliding income scale)		no	remain the same	not available	no	unknown
Connecticut	none	$473/month	$908/month	yes	remain the same	60 days	no	1%
Delaware	yes**	$1,900/month	$3,900/month	no	remain the same	14-21 days	no	< 10%
	** Diagnosis of end stage renal disease, receive kidney transplant, or be on dialysis. "The program is a Chronic Renal Disease Program."							
District of Columbia	"If the individual does not meet Medicaid eligibility criteria, the eligibility worker determines if [the client] is eligible for D.C. Medical Charities."^							
Idaho	"Local medical assistance programs require that Medicaid be denied before application for local assistance."^							
Maryland	none	$9,050/year	$11,330/year	no	remain the same (COLA adjustment)	not available	no	not available
Michigan	none	$246/month	N.A.***	yes	remain the same	45 days	no	unknown
	*** "We have no families receiving MAP. Income limit for two is $401 [per month]."							
Nebraska	yes~	$645/month (100% of federal poverty level)	$1,300/month	yes ($392 a month for 1 or 2 people)	remain the same	60 days	no	2%
	~ "Client must meet the SSI severity disability requirements but not the one year duration. They must be disabled for 180 days for the state program."							
New Jersey	none	~~	~~	yes (with a different program)	remain the same	not available	no	not available
	~~1-person household: $199/month employable; $269/month unemployable. 4-person household: $280/moth employable; $420/month unemployable.							
New York	"The application, review process, and collection of documentation are the same [as Medicaid]. Different income standards may apply."^							
Pennsylvania	"Applications for the state-funded MAP are taken at the same offices which handle Medicaid applications. The eligibility determination process is essentially the same as the Medicaid process."^							
Rhode Island	The state-funded MAP uses the same data base for [Medicaid] eligibility determination [to determine] if eligibility exists for Medicaid."^							
South Dakota	limited to inpatient hospital care	~~~	~~~	yes	more restrictive in 1997	30 days	no	not available
	~~"Eligibility is based on income and resources and compared to the household's monthly expenses. We compute the household's disposable income and determine how much the household should be able to pay on the hospital bill."							
Utah	none	$387/month (net income)	$602/month (net income)	yes	remain the same	30 days	no	<1%
Washington	yes#	$349/month	$349/month	not state program	remain the same	45 days	no	<1%
	#client must be incapacitated for 90 days							
Wisconsin	yes##	varies by county		varies by county	more restrictive in 1997	5 days	no	<1%
	##Counties administer the program and not all counties have a MAP or a comprehensive medical program. In some counties a person must be medically disabled; other counties do not have this medical eligibility requirement.							
Wyoming	none	100% federal poverty level	not applicable	no	remain the same	do not know	no	<1%

Note: All other states either did not have MAPs during 1997 or did not respond to the survey.
^These responses were to the 1995 survey of Medicaid eligibility administrators, not the 1997 survey of MAP administrators. The MAP administrators in these states did not respond to the 1997 survey.
Source: Robert J. Buchanan, Ph.D., Department of Community Health, University of Illinois, a 1997 survey of state program administrators, state-funded medical assistance programs. This research was funded by a grant from the Health Care Financing Administration, U.S. Department of Health and Human Services (grant # 18-P-90286/5-01).

applicant to deduct the cost of medical care from income levels and using this medical-cost adjusted income level for eligibility determination." This spend down provision allows people with higher incomes who have large medical expenses to qualify for MAP coverage. As Table 7-l documents, not all state-funded MAPs allow spend down as part of the eligibility determination process.

The state-funded MAPs in South Dakota and Wisconsin responded to the survey that compared to 1995, financial eligibility criteria became more restrictive during 1997, with eligibility standards remaining the same in the other states participating in the study. The questionnaire asked the MAP administrators to estimate the length of time for the eligibility process during 1996, from the submission of the application to the beginning of MAP benefits. Table 7-l presents these estimates of the number of days that eligibility determination took in the various states. No state reported a waiting list of people for MAP benefits during 1996. The eligibility section of the questionnaire concluded by asking the MAP administrators to estimate the number of people infected with HIV who received MAP benefits during 1996. As Table 7-1 illustrates, these state-funded MAPs did not serve large numbers of people with HIV during 1996. Typically less than one percent of MAP beneficiaries were infected with HIV, according to the estimates from the MAP administrators.

MAP Coverage of Health Services

The questionnaire provided the MAP administrators with the following list of health services, with a request to "please circle any of the following services covered and reimbursed by the MAP in your state during 1997:

physician services
emergency room services
X-ray services
substance abuse services
skilled nursing care at home
home aerosolized drug therapy
inpatient respite care
in-home diagnostic testing
home intravenous therapy
home-delivered meals
child care services
dental care
inpatient hospital care
clinic services
musing home care
mental health counseling
homemaker services
adult day care
durable medical equipment
rehabilitation services
transportation services
housing referrals
legal services
other (please describe):
outpatient hospital care
lab services
prescription drugs
home health aide
personal care services
in-home respite care
hospice care
case managers
benefits advocacy
HIV support groups
podiatry services

The survey responses, detailing the health services covered by the state-funded MAPs during 1997, are presented in Table 7-2. The range of MAP-covered services is comprehensive in most of the states.

MAP Health Services and HIV Care

Drug therapies for treatment of HIV infection and related opportunistic infections have emerged as the primary method for improving the quality of life and increasing the length of survival for people with HIV disease. Therapy with HIV protease inhibitors has been shown to decrease viral loads and elevate CD4 cell counts with relatively few adverse effects.[5,6] Recent studies demonstrate that these drugs, when used in combination with nucleoside antiretrovirals, slow the progression of HIV disease' and have beneficial effects lasting for as long as at least one year.' In addition, AIDS researchers presenting at an Interscience Conference on Antimicrobial Agents and Chemotherapy in Toronto, Canada in September, 1997 concluded that the three-drug therapy continues to fight off HIV in 79 percent of patients treated for two years and that the immune system strengthens the longer the drugs work.[9]

Various drug therapies are used to treat or prevent pneumocystis carinii pneumonia," toxoplasmosis," mycobacterium avium complex,[12] and CMV

Table 7-2
Health Services Covered by the MAP During 1997

	The Health Services Funded by the MAP During 1997:
Alaska	physician services, inpatient hospital care, nursing home care, transportation services, and prescription drugs
Arizona	physician services, emergency room services, X-rays, dental care (adults - emergency; children - full services), inpatient hospital care, clinic services, nursing home care (up to 90 days following hospitalization), durable medical equipment, transportation services, outpatient hospital care, lab services, prescription drugs, and podiatry services
California	The MAP is administered by counties and MAP policies for the coverage of health services are determined at the county level.
Colorado	physician services, emergency room services, X-rays, substance abuse services, dental care, inpatient hospital care, clinic services, mental health counseling, rehabilitation services, outpatient hospital care, lab services, prescription drugs, hospice care, case managers, benefits advocacy, and podiatry services
Connecticut	physician services, emergency room services, X-rays, substance abuse services, home aerosolized drug therapy, home intravenous therapy, dental care, inpatient hospital care, clinic services, mental health counseling, durable medical equipment, rehabilitation services, transportation services, outpatient hospital care, lab services, prescription drugs, home health aide, hospice care, and podiatry services
Delaware	transportation services, medications (prescription or over-the-counter), and nutritional supplements
District of Columbia	According to the 1995 survey of Medicaid eligibility administrators, the District of Columbia has a state-funded MAP However, the MAP administrators did not respond to the survey. According to the response to the Medicaid survey, the services covered by the MAP (D.C. Charities) in the District of Columbia are the same as the services covered by Medicaid.
Idaho	According to the 1995 survey of Medicaid eligibility administrators, Idaho has a state-funded MAP. However, the MAP administrators did not respond to the survey.
Maryland	prescription drugs
Michigan	physician services, emergency room services, X-rays, transportation services (emergency only), outpatient hospital care, lab services, prescription drugs, pap smears, mammograms, and immunizations
Nebraska	physician services, emergency room services, X-rays, substance abuse services (for under 21), skilled nursing care at home, home aerosolized drug therapy, inpatient respite care, in-home diagnostic testing, home intravenous therapy, child care services, dental care, inpatient hospital care, clinic services, nursing home care, mental health counseling, durable medical equipment, transportation services, outpatient hospital care, lab services, prescription drugs, home health aide, personal care services, hospice care, and podiatry services
New Jersey	physician services, X-rays, skilled nursing care at home, home aerosolized drug therapy, in-home diagnostic testing, home intravenous therapy, dental care, clinic services, nursing home care, mental health counseling, homemaker services, durable medical equipment, transportation services, lab services, prescription drugs, home health aide, personal care services, in-home respite care, hospice care, case managers, and podiatry services
New York	According to the 1995 survey of Medicaid eligibility administrators, New York has a state-funded MAP. However, the MAP administrators did not respond to the survey.
Pennsylvania	According to the 1995 survey of Medicaid eligibility administrators, Pennsylvania has a state-funded MAP. However, the MAP administrators did not respond to the survey.
Rhode Island	According to the 1995 survey of Medicaid eligibility administrators, Rhode Island has a state-funded MAP. However, the MAP administrators did not respond to the survey.
South Dakota	physician services, emergency room services, X-rays, dental care, inpatient hospital care, clinic services, nursing home care, durable medical equipment, outpatient hospital care, lab services, and prescription drugs,
Utah	physician services, emergency room services, X-rays, skilled nursing care at home, in-home diagnostic testing, home intravenous therapy, dental care, clinic services, nursing home care, transportation services, outpatient hospital care, lab services, prescription drugs, and podiatry services
Washington	none mentioned in survey response
Wisconsin	physician services, emergency room services, X-rays, home aerosolized drug therapy, inpatient respite care, in-home diagnostic testing, home intravenous therapy, home-delivered meals, dental care, inpatient hospital care, clinic services, durable medical equipment, rehabilitation services, transportation services, housing referrals, outpatient hospital care, lab services, prescription drugs, hospice care, case managers, benefits advocacy, and podiatry services*
	*("Counties in Wisconsin define what medical services will be offered by the county. Counties can choose to offer comprehensive services or no services at all. Counties also define eligibility criteria.")
Wyoming	prescription drugs and oxygen

Note: All other states either did not have MAPs during 1997 or did not respond to the survey.

Source: Robert J. Buchanan, Ph.D., Department of Community Health, University of Illinois, a 1997 survey of state program administrators, state-funded medical assistance programs. This research was funded by a grant from the Health Care Financing Administration, U.S. Department of Health and Human Services (grant #18-P-90286/5-01).

retinitis.[13] Infusions of interleukin-2 produced substantial and sustained increases in CD4 counts with no increase in plasma HIV RNA levels in patients with HIV.[14] The incidence rates of a number of opportunistic infections among people with HIV have declined over the past five years and are being diagnosed at a later stage of HIV disease due to the effective use of antiviral drugs, targeted preventive therapy, and more comprehensive clinical management of the disease?

Given the importance of drug therapies to HIV care, the survey asked the administrators if the MAP in their state covered prescription drugs during 1997, with all MAPs reporting coverage of prescription drugs The administrators also were asked if the MAP in their state has a drug formulary, defined as "a list of selected drugs that the program covers." Not all state-funded MAPs implemented formularies, as Table 7-3 documents. However, the questionnaire asked if during 1997 the MAP in their state covered all drugs approved by the Food and Drug Administration (FDA) HIV-related conditions and treatments? As Table 7-3 demonstrates, the state-funded MAPs generally covered all drugs approved by the FDA for HIV-related treatments and conditions. Alaska responded to this question that coverage is "based on [the] need for 'specific services [and] not linked to HIV."

The questionnaire asked the administrators to identify "the most effective services at meeting the health care needs of people with HIV-related illnesses" from all services covered by the MAP in their state during 1997. As Table 7-3 illustrates, prescription drugs and physician services were the most frequently mentioned MAP-covered services that are beneficial to HIV care.

The survey asked the administrators if the MAP in their state covered the use of any service when a Medicaid recipient had care needs in excess of any Medicaid

Table 7-3
MAP Coverage of Effective Health Services for People with HIV and Coordination with Mediiid During 1997

	Does the MAP Have a 1997 Drug Formulary?	Are All FDA-Approved Drugs for HIV Covered?	Of All Services Covered by the MAP, the Most Effective for HIV Care Are:	If Medicaid Limits Utilization of Care Does the MAP Cover Services in Excess of Medicaid Limits?	Does the MAP Cover HIV-Related Services Not Covered by Medicaid?
Alaska	no	no*	no answer given	no	no
	*"Eligibility is based on the need for specific services and is not linked to HIV."				
Arizona	no	yes	data not available	no Medicaid utilization limits	no
California	The MAP is administered by counties and MAP policies for the coverage of health services are determined at the county level.				
Colorado	no	unknown	data not available	no (a person is not eligible for both the MAP and Medicaid)	no
Connecticut	yes	yes	**	no Medicaid utilization limits	no
	**"Drug therapy is helpful, as are all other services provided, depending on the individual's situation/needs/treatment plan."				
Delaware	yes	yes	medications and nutritional supplements	no Medicaid utilization limits	yes - nutritional supplements
District of Columbia	According to the 1995 survey of Medicaid eligibility administrators, the District of Columbia has a state-funded MAP. However, the MAP administrators did not respond to the survey.				
Idaho	According to the 1995 survey of Medicaid eligibility administrators, Idaho has a state-funded MAP. However, the MAP administrators did not respond to the survey.				
Maryland	yes	no answer	program covers only pharmacy services	no Medicaid utilization limits	no
Michigan	yes	"Most are covered, based on pre-scriber request."	none mentioned	no	no
Nebraska	no	yes	physician visits	no Medicaid utilization limits	no answer
New Jersey	no	yes	unknown	no ("We follow the same guidelines as Medicaid on utilization limits.")	no answer
New York	According to the 1995 survey of Medicaid eligibility administrators, New York has a state-funded MAP. However, the MAP administrators did not respond to the survey.				
Pennsylvania	According to the 1995 survey of Medicaid eligibility administrators, Pennsylvania has a state-funded MAP. However, the MAP administrators did not respond to the survey.				
Rhode Island	According to the 1995 survey of Medicaid eligibility administrators, Rhode Island has a state-funded MAP. However, the MAP administrators did not respond to the survey.				
South Dakota	yes	yes	no answer	some counties use Medicaid limits, others do not	no
Utah	same formulary as Medicaid	yes	physician services and prescription drugs	no	no
Washington	yes	yes	case management	***	yes - alternative treatment providers~
	****Services are based on medical necessity. Limitations are placed on certain services, i.e., therapy, but additional services can be obtained through and Exception to the Policy."				
	~Examples of alternative treatment providers are naturopath and chiropractor services for adults				
Wisconsin	no	generally yes~~	physician services and prescription drugs	yes, with prior authorization	~~~
	~~"Generally yes in those counties that provide such services."				
	~~"The MAP generally covers the same services as [Medicaid] does. However, some counties limit services to those covered by [Medicaid] and others do not."				
Wyoming	no	yes	prescription drugs	no	no

Note: All other states either did not have MAPs during 1997 or did not respond to the survey.

Source: Robert J. Buchanan, Ph.D., Department of Community Health, University of Illinois, a 1997 survey of state program administrators, state-funded medical assistance programs. This research was funded by a grant from the Health Care Financing Administration, U.S. Department of Health and Human Services (grant # 18-P-90286/5-01).

limits. As Table 7-3 indicates, there were no Medicaid utilization limits during 1997 in many of the states with state-funded MAPs. Wisconsin reported, however, that the state-funded MAP in that state can supplement Medicaid coverage with prior authorization. In another Medicaid-related question, the administrators were asked if the state-funded MAP covered any health service often needed by people with HIV-related illnesses that the state Medicaid program does not cover. The state-funded MAP in Delaware reported the coverage of nutrition supplements and the MAP in Washington State reported coverage of alternative treatments such as naturopath and chiropractor services for adults.

MAP Payment Levels

To assess the payment levels for health services implemented by the state-funded MAPs, the MAP administrators were asked to compare the MAP payment to the Medicaid payment in their state for inpatient hospital care, physician sewices,and home health services. These are health services often needed by people with HIV disease. The questionnaire presented the following options for survey responses for each of the three health services:

less than 50% of Medicaid rate	SO-90% of Medicaid rate	91-110% of Medicaid rate
111-150% of Medicaid rate	over 150% of Medicaid rate	no MAP coverage of this service

As Table 7-4 documents, the MAP payment levels during 1997 were typically below the Medicaid payment level for each of the three health services in most of the states reporting data. The state-funded MAPs in Arizona and Connecticut responded to the survey that the MAP payments are equal to the Medicaid payment levels. The MAP in Wisconsin responded that “state law limits the MAP payment to ‘at or below’ the Medicaid rate. Some counties pay the Medicaid rate, other counties pay a lower

Table 7-4
MAP Payments for Selected Health Services During 1997: A Comparison with Medicaid

	Comparison of the 1997 MAP Payment for Inpatient Hospital Care to the Medicaid Level:	Comparison of the 1997 MAP Payment for Physician Services to the Medicaid Level:	Comparison of the 1997 MAP Payment for Home Health Services to the Medicaid Level:
Alaska	less than 50% of Medicaid rate	91-1 10% of Medicaid rate	no MAP coverage of this service
Arizona	payments are the same	payments are the same	no MAP coverage of this service
California	The MAP is administered by counties and MAP payment policies are determined at the county level.		
Colorado	The MAP contracts with hospitals	Physicians are paid by the hospitals	no MAP coverage of this service
Connecticut	rates identical to Medicaid rates	rates identical to Medicaid rates	rates identical to Medicaid rates
Delaware	no MAP coverage of this service	no MAP coverage of this service	no MAP coverage of this service
District of Columbia	According to the 1995 survey of Medicaid eligibility administrators, the District of Columbia has a state-funded MAP. However, the MAP administrators did not respond to the survey.		
Idaho	According to the 1995 survey of Medicaid eligibility administrators, Idaho has a state-funded MAP. However, the MAP administrators did not respond to the survey. According to the response to the Medicaid survey, the Idaho MAP reimburses providers with Medicaid rates.		
Maryland	no MAP coverage of this service	no MAP coverage of this service	no MAP coverage of this service
Michigan	no MAP coverage of this service	5090% of Medicaid rate	no MAP coverage of this service
Nebraska	50-90% of Medicaid rate	50-90% of Medicaid rate	50-90% of Medicaid rate
New Jersey	data not available	data not available	data not available
New York	According to the 1995 survey of Medicaid eligibility administrators, New York has a state-funded MAP. However, the MAP administrators did not respond to the survey.		
Pennsylvania	According to the 1995 survey of Medicaid eligibility administrators, Pennsylvania has a state-funded MAP. However, the MAP administrators did not respond to the survey.		
Rhode Island	According to the 1995 survey of Medicaid eligibility administrators, Rhode Island has a state-funded MAP. However, the MAP administrators did not respond to the survey.		
South Dakota	less than 50% of Medicaid rate	less than 50% of Medicaid rate	no MAP coverage of this service
Utah	no MAP coverage of this service	91-110% of Medicaid rate	91-1 10% of Medicaid rate
Washington	no answer	no answer	no answer
Wisconsin	5090% of Medicaid rate*	91-1 10% of Medicaid rate*	50-90% of Medicaid rate*
	*State law limits the MAP payment to "at or below" the Medicaid rate. Some counties pay the Medicaid rate, other counties pay a lower rate.		
Wyoming	no MAP coverage of this service	no MAP coverage of this service	no MAP coverage of this service

Note: All other states either did not have MAPs during 1997 or did not respond to the survey.

Source: Robert J. Buchanan, Ph.D., Department of Community Health, University of Illinois, a 1997 survey of state program administrators, state-funded medical assistance programs. This research was funded by a grant from the Health Care Financing Administration, U.S. Department of Health and Human Services (grant # 18-P-90286/5-01).

rate." These relatively low MAP payment levels may make it difficult for MAP beneficiaries to gain access to health services. For example, lower Medicaid payment levels have affected the physician services available to Medicaid recipients, with fewer physicians participating in Medicaid in states with lower physician payment levels and physicians who do participate limit their practice by treating fewer Medicaid patients.[16] In addition, in states with Medicaid payment levels that are lower than other insurer's rates, Medicaid patients tend to receive care from high volume Medicaid practices, hospital outpatient departments, emergency rooms, or local health department clinics.[17]

MAP Utilization Limits

The survey asked the administrators if the state-funded MAP set "limits to the benefits that a MAP beneficiary may receive (e.g., six months of health coverage or $2,500 in expenditures for care) from this program? As Table 7-5 presents, the majority of state-funded MAPs did not limit the benefits a MAP beneficiary could receive during 1997. Some of the state-funded MAPs which limited benefits allowed exemptions to these limits for medical necessity and other MAPs did not. A similar question asked about MAP utilization limits, with the responses summarized in Table 7-5.

The survey concluded by asking the administrators to compare MAP spending levels in their state for fiscal year 1996 to MAP spending levels for fiscal year 1997. The questionnaire offered the following options for responses:

___ increase 0 - 5% ___ increase 6 - 10% ___ increase over 10% ___ no change

___ decrease 0 -5% ___ decrease 6 - 10% ___ decrease over 10%

Table 7-5
Utilization Limits on MAP Coverage and MAP Spending Levels During 1997

	Are There Limits to MAP Benefits During 1997?	If Yes, Are There Exceptions for Medical Necessity?	Are There Utilization Limits for Health Services During 1997?	If Yes, Are There Exceptions for Medical Necessity?	MAP Spending Levels for Fiscal Year 1997 Compared to 1996 Levels:
Alaska	8 days inpatient care 12 physician visits	no	8 days inpatient care 12 physician visits	no	decrease over 10% in 1997
Arizona	eligibility reviewed every 6 months	no	no	not applicable	increase 0-5% in 1997
California	The MAP is administered by the counties and MAP utilization policies are determined at the county level.				
Colorado	no	not applicable	no	not applicable	increase 0-5% in 1997
Connecticut	no	not applicable	no	not applicable	decrease 6-10% in 1997
Delaware	no - based on continued financial need	not applicable	no	not applicable	increase over 10% in 1997
District of Columbia	According to the 1995 survey of Medicaid eligibility administrators, the District of Columbia has a state-funded MAP. However, the MAP administrators did not respond to the survey.				
Idaho	According to the 1995 survey of Medicaid eligibility administrators, Idaho has a state-funded MAP. However, the MAP administrators did not respond to the survey.				
Maryland	no	not applicable	no	not applicable	unknown
Michigan	no	not applicable	no	not applicable	increase 6-10% in 1997
Nebraska	no	not applicable	no	not applicable	increase 0-5% in 1997
New Jersey	no	not applicable	no	not applicable	increase over 10% in 1997
New York	According to the 1995 survey of Medicaid eligibility administrators, New York has a state-funded MAP. However, the MAP administrators did not respond to the survey.				
Pennsylvania	According to the 1995 survey of Medicaid eligibility administrators, Pennsylvania has a state-funded MAP. However, the MAP administrators did not respond to the survey.				
Rhode Island	According to the 1995 survey of Medicaid eligibility administrators, Rhode Island has a state-funded MAP. However, the MAP administrators did not respond to the survey.				
South Dakota	no	not applicable	counties may establish their own limits	no answer	increase 0-5% in 1997
Utah	no	not applicable	no	not applicable	no change
Washington	yes/no*	yes	**	yes	increase 6-10% in 1997
	*This is a yes and no question. No, as long as the client remains eligible for a MAP. There is no cap dollar amount limitation under the current fee-for-service reimbursement system. Yes, there are limitations within state-funded programs, i.e., Medically Indigent - eligible if condition is acute and emergent and the person meets the financial criteria.				
	** therapies limited to 12 visits per year, psychological evaluation - once per year, and psychiatric visit - 1 hour/month				
Wisconsin	yes***	yes	yes~	yes	decrease over 10% in 1997
	***Some counties have no limits, while others have dollar limits. Most have a county residence requirement and duration limits."				
	~"No state limits, but some counties limit utilization with prior authorization or time or eligibility limits."				
Wyoming	3 prescriptions per month	no	3 prescriptions per month	no	decrease over 10% in 1997
Note: All other states either did not have MAPs during 1997 or did not respond to the survey.					
Source: Robert J. Buchanan, Ph.D., Department of Community Health, University of Illinois, a 1997 survey of state program administrators, state-funded medical assistance programs. This research was funded by a grant from the Health Care Financing Administration, U.S. Department of Health and Human Services (grant # 18-P-90286/5-01).					

As Table 7-5 illustrates, the majority of states responding to the survey reported that MAP spending levels increased in 1997 compared to 1996 levels. However, three ofthe four states reporting decreased MAP spending in 1997 noted that this decrease was over 10 percent. In contrast, half of the states reporting increased spending in 1997 indicated that the increase was five percent or less.

Summary and Conclusions

A number of states implement state-funded MAPs to provide health care to low-income people. However, a review of the literature revealed no published papers that describe these programs. A two-step survey process was used to identify states that implemented state-funded MAPs during 1997 and to collect data describing eligibility, coverage, and payment policies for these programs.

Typically, eligibility requirements for these programs are restrictive but the range of health services covered tends to be comprehensive in most states. MAP payment levels for the health services included in the study typically are less than the Medicaid payment level, which may make it difficult for MAP beneficiaries to gain access to these services. In spite of these eligibility and payment level restrictions, these state-funded MAPs can provide health coverage to people with HIV disease who lack other health insurance. As Table 7-2 illustrates, most of these state-funded MAPs cover a comprehensive range of health services needed by people infected with HIV, including acute care services and prescription drugs, as well as necessary home and community-based care and support services.

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Chapter 8
Assessments of the Coverage of HIV-Related Care by Public Programs: A Survey of AIDS Service Organizations*

Introduction

Public programs are the primary payers of the health care provided to people infected with HIV. A study of over 5,800 people who were HIV positive found that public programs provided health coverage to 53 percent of these people in 1991.' The same study discovered that these public programs play an even greater role in the coverage of the sickest HIV-infected patients, paying for the health care of 62 percent of people with full-blown AIDS. In addition to the state Medicaid programs (the largest public payer of AIDS-related care), the Medicare program and the programs funded by Titles I and II of the Ryan White CARE Act are important payers of this care. Given the importance of the public programs in paying for HIV-related care, how effective are these programs at meeting the needs of people with HIV illness? To gain insight into how public programs meet the care needs of people with HIV illness, a group of AIDS service organizations (ASOs) were surveyed. This research presents the results of that survey.

Background

The Ryan White CARE Act Programs

Title I of the Ryan White CARE Act provides funds to eligible metropolitan areas (EMAs) with the largest number of AIDS cases. EMAs are required by the CARE Act to provide a continuum of outpatient and ambulatory health and support services to

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[a] **This research currently is under publication review at a health policy journal.**

people with HIV, including case management services and comprehensive treatment.* Title II of the CARE Act allocates funds to the states to provide HIV-related medical and support services, allowing the states to implement HIV consortia programs, HIV/AIDS drug assistance programs, home and community-based care programs, and health insurance continuation programs.[3]

HIV consortia funded by Title II of the CARE Act can provide a number of services to eligible people with HIV. For example, HIV consortia in many states provide case management services, primary medical care, personal care, transportation services, nutritional services, and housing assistance.[4] The Title II program also funds HIV/AIDS drug assistance programs, with the number and scope of covered medications varying by state.[5] The home and community-based care (H&CBC) programs funded by Title II can provide a range of services to eligible people with HIV. These Title II H&CBC programs, which are implemented in a number of states, fund a range of services, among those beneficial to people with HIV are: durable medical equipment, in-home diagnostic testing, comprehensive nurse case management, attendant care, day treatment services, personal care, and housing assistance.[6] The health insurance continuations programs funded by Title II cover health insurance premiums in all states offering this program and may also cover copayments, coinsurance, and/or deductibles.[7]

The State Medicaid Programs

Financial eligibility requirements for Medicaid vary from state to state, with eligibility potentially available to low-income elderly, blind, and disabled people, as well as to anyone receiving benefits from the Aid to Families with Dependent Children program.' As a result of a ruling by the Social Security Administration, people with a

diagnosis of AIDS are presumed to meet the disability standard.' In July, 1993 the Social Security Administration published a listing of HIV-related conditions that can be used to establish presumptive disability for people infected with HIV but without a diagnosis of AIDS."

The state Medicaid programs must cover and reimburse inpatient and outpatient hospital care, physician services, rural clinic services, laboratory services, and x-ray services for eligible recipients. In addition, the state Medicaid programs have the option to cover prescription medications, clinic services, diagnostic services, screening services, personal care, transportation to health care, and case management services.[11] A number of state Medicaid programs have developed innovative policies designed to provide the hospital care,[12] the home health and hospice care,[13] the nursing home care,[14] the physician services,[15] and prescription drugs" needed by people with AIDS, as well as provide needed services with the Medicaid home and community-based care waiver programs.[17]

The Medicare Program

In addition to the elderly, Medicare coverage is potentially available to the disabled if they meet certain work-related requirements. For a person with HIV to become eligible for Medicare requires meeting eligibility criteria for Social Security Disability Insurance (SSDI), including disability status (similar to Medicaid, people with AIDS have presumptive disability), sufficient work-related history, and a 29-month waiting period (5 months from disability status for SSDI payment to begin, then 24 additional months for Medicare coverage to begin).[18] Although not a major payer of the care needed by people with AIDS, the Medicare program can be a source of funding for inpatient and outpatient hospital care, as well as physician services and

diagnostic, lab, and x-ray services for people who are eligible for benefits. However, the Medicare program does not cover and reimburse outpatient prescription drugs.

Methodology

Organizations Surveyed

A list of organizational affiliates was obtained from the National Association of People with AIDS (NAPWA) to identify ASOs to include in the study. In identifying the ASOs to include in the survey, and to achieve a broadly-based study, the objective was to include at least one AS0 from each state as well as one AS0 from each of the 56 EMAs (not including Puerto Rico) funded by Title I of the Ryan Write CARE Act during 1996. In a number of states the AS0 from a Title I EMA was the only NAPWA-affiliated AS0 in the state and was used to represent both the EMA and the state in the survey group. In more populated states, ASOs from EMAs and non-EMA areas were included in the survey group. (Many states do not have Title I EMAs.)

The list of NAPWA organizational affiliates did not have ASOs for eight states. (These states all had small populations and were typically from the western or central regions of the United States.) In addition, the NAPWA list did not have ASOs for 14 EMAs (typically these EMAs were regional areas or counties, not cities.) To try to include ASOs from these missing states and EMAs in the survey, telephone directories were used for the largest city in these states and EMAs to identify ASOs. A total of 87 ASOs in 47 states and the District of Columbia were identified and included in the initial survey group. (ASOs could not be identified in North Dakota, Rhode Island and South Dakota.) The executive director or president of the AS0 was typically identified as the person to receive the questionnaire.

Survey Questionnaire

A five-page questionnaire was developed for the study using an open-ended format, focusing on the Medicaid programs, the Medicare program, and the programs funded by Titles I and II of the Ryan White CARE Act. For each of these four programs the questionnaire asked the executive director of the AS0 "to list the health and care related services covered by" that program in their state "that are effective at meeting the needs of people with HIV illness." In addition, the questionnaire asked the AS0 to "list any health and care-related services not covered by" that program in their state 'that would be effective at meeting the needs of people with HIV illness!' The questionnaire also asked the AS0 to 'mention any problems or difficulties that people with HIV illness have with" these programs in their state.

The questionnaire presented a list of options to the AS0 concerning any possible identification of the AS0 in reports or publications resulting from the survey to assure the degree of anonymity that the organization preferred. The questionnaire concluded by asking the person completing the questionnaire to "describe your role in the organization."

Survey Process

In late February, 1997, the first mailing of the questionnaire was sent to the 87 ASOs included in the survey group. Eight questionnaires were returned by the U.S. Postal Service as undeliverable, with no forwarding address. Directory assistance had no telephone listing for these ASOs in the cities listed in the old addresses. These eight ASOs were dropped from the survey group, reducing the group to 79 ASOs. In addition, two organizations responded to the survey that they were not involved with the health services and care needs of people with HIV illness, and hence, did not think

that they were qualified to respond. Also, two ASOs responded that they are understaffed and lacked the personnel to complete the survey. The final survey group contained 75 ASOs. Three additional mailings of the questionnaire were sent to ASOs at approximately six-week intervals, with the last mailing sent in early August, 1997.

Survey Responses

By September, 1997 30 ASOs (40 percent of the survey group) completed and returned questionnaire, providing data on these public programs in 24 states. Many of the ASOs participating in the study did not want their identity or state revealed. However, these 30 ASOs are from all regions and geographic areas of the United States. Of these 30 ASOs, six people responding identified themselves as the executive director, four as case managers, two as director of public policy, two as director of client services, and two as staff members. Other people responding identified themselves as chief operating officer, chair, vice-president, board member, or coordinator. Nine people completing and returning questionnaires did not identify their role in the ASO.

Survey Results - The Medicaid Program

Effective 'Services Covered

The questionnaire asked the ASOs to "list the health and care-related services covered by the Medicaid program in your state that are most effective at meeting the needs of people with HIV illness". Table 8-1 presents the 10 most frequently listed health and care-related services in the survey responses, with prescription drug coverage mentioned most frequently (by 24 ASOs). An AS0 from Utah responded

Table 8-I: The Medicaid Program

A.) Effective Health and Care-Related Services for People with AIDS

Rank

1. prescription drugs/medications (24)
2. primary care/primary physician (18)
3. home care/home health aide/personal care aide/skilled nursing/attendant care/chore services (12)
4. inpatient hospital care (11)
5. lab services/diagnostic testing (6)
6. dental care (6)
7. hospice (4)
7. eye care/eye exam/optical care (4)
7. nursing home care (4)
7. outpatient hospital care (4)

B.) Effective Health and Care-Related Services for People with AIDS Not Covered

1. dental care/dental services (8)
2. mental health/pyscho-social care (5)
2. restrictive/limited coverage of prescription drugs (5)
4. assisted living facilities/residential care facilities/housing (3)
4. restrictive/limited coverage of physician services (3)
4. alternative treatments (acupuncture/massage therapy) (3)
7. home health care/limited home health care (2)
7. hospice (2)
7. nutritional supplements (2)

C. Problems with Medicaid Encountered by People with AIDS

1. application process/length of application process/restrictive Medicaid income eligibility guidelines (17)
2. spend down paperwork/spend down levels (11)
3. limited coverage of medications/prescription drugs (4)
4. HMOs/managed care implementation (3)
4. limited physician participation in Medicaid (3)
4. Medicaid coverage taken away when SSDI approved, but Medicare coverage does not begin for 2 more Years (3)
7. many people with HIV (but not AIDS) not covered by Medicaid, delaying access to care (2)

Note: the number in parentheses following each health or care-related service is the number of ASOs mentioning the service.

that the "Utah Medicaid [program] has a long history of providing reimbursement for quality HIV care. ... Medicaid has worked hard to talk with major HIV providers to establish and maintain treatment." Similarly, an AS0 in Mississippi reported that "Medicaid is the best coverage for low income persons without health insurance in Mississippi, although [Medicaid coverage] is limited."

Other effective covered services that were mentioned in survey responses from the ASOs (with the frequency following each service in parenthesis) are: transportation to care/ambulance (3); case management (2); durable medical equipment (2); health insurance continuation (2); home and community-based care waiver programs (2); speech/hearing/physical therapy (2); substance abuse services (2); home-delivered meals (1); limited mental health (1); and nutrition supplements (1).

Effective **Services Not Covered**

The questionnaire asked the ASOs to "list any health and care-related services that the Medicaid program in your state does NOT cover that would be effective at meeting the needs of people with HIV illness". As Table 8-1 illustrates, dental care was the most frequently mentioned effective service that was not covered by the state Medicaid programs (mentioned by 8 ASOs).

A number of ASOs mentioned restrictive coverage of prescription drugs and physician services in response to this question. Federal Medicaid policy allows the states to establish utilization limits on the number of physician visits[19] and prescription drugs[20] that Medicaid recipients may receive. An AS0 in Texas responded that Medicaid coverage of prescription drugs in Texas as of August, 1997 was "far too restrictive (3 per month per recipient) to provide people with HIV/AIDS with the medications they need. ([However, this is] changing as the Texas Medicaid

program reorganizes its drug programs to provide unlimited prescriptions for Medicaid recipients.) Because of this [limit on prescriptions], many clients in this service area get health care from more than one source, resulting in fragmented, sometimes duplicated, and inadequately supervised care." An AS0 from South Carolina replied that Medicaid coverage of prescription drugs is limited to 3 prescriptions per month in that state. 'Those on the HIV/AIDS [home and community-based care] waiver program qualify for 5 prescriptions [per month], but these [people] are more and more those at the end stage when treatments are less effective." The ASOs mentioning this restrictive coverage point out that although these services may be covered by Medicaid, the utilization limits imposed by a number of states can be below the level of care needed by people with HIV illness.

Other effective services not covered by Medicaid that were mentioned by only one AS0 in the survey process are: assistance with activities for daily living; early intervention services; eye care; food; limited lab services; limited hospital care; and transportation to health care. An AS0 from Nebraska responded that the Nebraska Medicaid program does not provide transportation to or from medical appointments, creating "severe problems for disabled [Medicaid recipients] who cannot access infectious disease specialists due to great distances." Aloysius Home, as AS0 in Tennessee replied that there is "no reimbursement for supportive or assisted living facilities such as Aloysius Home. Research from other parts of the country has shown that programs such as ours decrease the number and length of hospitalizations for persons with HIV illness."

All of these effective services not covered by Medicaid, as well as the effective services not covered by Medicaid that are listed in Table 8-1, can be provided to

Medicaid recipients with AIDS through the Medicaid home and community-based care waiver programs.[21] Expanded use of these waiver programs will allow the state Medicaid programs to broaden coverage of the health and care-related services to meet the care needs of people with AIDS.

In addition, one AS0 responded to this question that there is no Medicaid coverage for people with HIV (without AIDS) who do not meet other eligibility criteria. Unlike AIDS, merely being infected with HIV does not confer presumptive disability for Medicaid eligibility. Unfortunately, unless eligible through some other category (for example, Aid to Families with Dependent Children) people infected with HIV (without a diagnosis of AIDS) are not eligible for Medicaid. Without Medicaid, or some other type of coverage, it will be difficult for people with HIV to gain access to the combination drug therapies that are effective at combatting the progression of HIV disease.

Problems with Medicaid

The questionnaire asked the **ASOs** to "mention any problems or difficulties that people with HIV illness have with the Medicaid program in your state". As Table **8-1** presents, by far, the **eligibility** process was the most frequently mentioned problems that people with HIV illness encounter with the Medicaid program. The complexity of the Medicaid application process, the length of this process, and restrictive income eligibility guidelines were mentioned most frequently by the **ASOs** as a problem people with HIV illness have with Medicaid.

Another Medicaid problem for people with HIV illness is the **eligibility** issue of "spend down," as Table **8-1** documents. Many state Medicaid programs cover the optional medically needy category of Medicaid recipients. The medically needy meet certain eligibility guidelines for Medicaid coverage, yet have financial assets and

income in excess of Medicaid limits.[22] State Medicaid programs offering medically needy coverage allow these people to deduct the costs of their health care from their incomes and assets to "spend down" to Medicaid eligibility. Eleven ASOs noted that the paperwork required for the administration of the spend down process is a problem for people with HIV illness and that the spend down levels can be burdensome.

One AS0 provided a detailed explanation of the spend down problem. In that state the cut off income level for Medicaid eligibility is $755 per month. "A client earning that amount or less is entitled to Medicaid. However, if one earns $756 per month, he must spend down to $418 on medical expenses each month, and show proof of same, prior to being eligible for Medicaid. Not only is this unfair, $1 more [income] costs a client over $300 more each month, but the tracking of eligibility leaves room for 'computer errors' where the computer still says the client is not eligible even though he has met his spend down [requirements] causing difficulty getting medications and/or services."

An AS0 in Wyoming responded that Medicaid coverage is offered to some people with AIDS at the beginning of the eligibility process for Social Securii disability coverage. However, when a person is determined eligible for Social Security Disability Insurance, the higher income results in the loss of Medicaid coverage. These people have no health coverage for two years until Medicare coverage begins. Hence, Medicaid coverage "is denied at a time when many people could most use it."

Three ASOs mentioned the problems that Medicaid recipients with HIV illness have with managed care or health maintenance organizations (HMOs). For example, an AS0 in Utah replied that Medicaid coverage is "in some instance better than HMO/AIDS care." In addition, an AS0 from Florida reported that the "Medicaid HMO

makes it difficult for people living with HIV to see the specialists who manage their care. Most primary cafe providers are not knowledgeable about HIV/AIDS care and still do not provide referrals for patients [with HIV] easily."

Other problems or difficulties that people with HIV illness have with Medicaid that were mentioned by only one AS0 in the survey process are: administrative problems with health insurance continuation; authorization of payments for medications; confidentiality; implications of new insurance "portability" law are unclear; limited home health care; limited lab tests; limited coverage of oxygen services; limited nursing home beds covered; many patients must seek services at two or more sites for needed care, resulting in fragmented and uncoordinated care; Medicaid cutbacks have unclear implications for people with AIDS; and the waiting time to receive home and community-based care waiver services due to inadequate funding and staffing.

Survey Results: Title II of the Ryan White CARE Act

Effective Services Covered

The questionnaire asked the ASOs to list the health and care-related services covered by programs funded by Title II of the Ryan White CARE Act that are effective at meeting the care needs of people with HIV illness. Table 8-2 presents the mostly frequently mentioned health and care-related services, with prescription drug coverage mentioned most frequently (by 17 ASOs). Interestingly, food and nutrition (mentioned by 13 ASOs), alternative therapies (4 ASOs), and legal services (4 ASOs) are effective care or services covered by programs funded by Title II of the CARE Act that are not covered by the traditional state Medicaid programs but may be covered by the Medicaid home and community-based care waiver programs?

Table 8-2: Tie II of the Ryan White CARE Act

A) Effective Health and Care-Related Services for People with AIDS

Rank

1. prescription drugs/medications (17)
2. primary care/clinical services (14)
3. food and nutrition (13)
4. case management (9)
5. mental health/counseling/support groups (8)
6. dental care (7)
7. transportation services (6)
8. alternative therapies (acupuncture/herbal or massage therapy (4)
8. legal services (4)
9. health insurance continuation (3)
9. home health services (3)

B.) Effective Health and Care-Related Services for People with AIDS Not Covered

1. alternative therapies (5)
1. mental health/pyscho-social services/support groups (5)
3. limited drug formulary/psychiatric drugs/more funding for drugs (4)
3. limited utilization of services/limited funding (4)
5. assisted living facilities/housing (2)
5. inpatient care (2)

C. Problems with Tie II Encountered by People with AIDS

1. limited funding for Tie II programs (11)
2. lack of awareness of Tie II programs/services (4)
3. access to services (2)
3. bills paid slowly (2)
3. lack of a good process for inputs into the allocation of funds for programs/services and for planning (2)
3. people with health insurance cannot use Tie II services (2)

Note: the number in parentheses following each health or care-related service is the number of ASOs mentioning the service.

Other effective covered services mentioned in the survey responses from the ASOs (with the frequency following each service in parenthesis) are: benefits advocacy (2); financial assistance (2); social services (2); day care (adult and child) (2); durable medical equipment (2); emergency housing (2); hospice (2); respite care (2); substance abuse services (2); early intervention services (1); foster care/adoption (1); HIV counseling/testing (1); hepatitis B counseling/testing/vaccine (1); home infusion (1); outreach programs (1); rehabilitation therapy (1); respiratory treatment (1); and TB counseling and testing.

Effective Services Not Covered

The questionnaire asked for a listing of any health or care-related services that programs funded by Title II of the CARE Act do not cover that would be effective at meeting the needs of people with HIV illness. The responses from the ASOs are presented in Table 8-2, with alternative therapies the most frequently mentioned beneficial health service not covered by programs funded by Title II of the CARE Act. This illustrates that the health and care-related services covered by Title II programs vary from state to state, as four other ASOs from other states listed alternative therapies among the most effective health services covered by the Title II program in their states.

Other effective services not covered by Title II programs that were mentioned by only one AS0 in the survey process are: education/training support groups; eye care; food; HIV prevention programs; health insurance continuation for people with HIV (not AIDS); hospice; limited case management and coordination of services; limited financial assistance; limited transportation services; local consortia set priorities - services vary widely among consortia across the state; no centralized statewide drug

assistance program; ongoing assistance; only case management funded - any other Title II program would be beneficial; and substance abuse services.

One AS0 responded to this survey question that the programs funded by Title II of the CARE Act need to address the concerns of people who may recover from HIV-related disability with jobs programs and re-education programs. Given the success of the combination drug therapies in combatting the progression of HIV disease in many people,[24] the needs of people who recover from HIV-related disability could become an increasingly common problem. Not only will they need job and education programs as the AS0 pointed out, but will they lose eligibility for Medicaid, Medicare, or the Ryan White programs? If people who recover from HIV-related disability lose eligibility for Medicaid or the drug assistance programs funded by Title II of the CARE Act, they may not be able to continue the combination drug therapies that allowed their recovery.

Problems with the Title II Programs

The questionnaire asked the people at the ASOs to mention any problems or difficulties that people with HIV illness have with the Title program in their state. As Table 8-2 illustrates, limited funding for Title II programs was by far the most frequently mentioned problem (11 ASOs). An AS0 in South Carolina replied that the limitations on funding "restrict care from standards often suggested." Another AS0 responded that "as a low incidence [of AIDS] state, our funds are very limited - we cannot meet the needs of everyone who is eligible." An AS0 from Iowa reported that a major problem people with HIV illness have with the Title II program is "being denied payment because the client is over the $500 limit per quarter or because the client is trying to get payment for a drug not on the formulary (for example, psychiatric

medications)." An AS0 from Mississippi answered that "now only the triple **drug combination is furnished to as many people as the** money will cover." A Wyoming AS0 concluded that "in a lot of cases it would be better to have more [funds] for medical care as the prescription drug portion can be eaten up in one month."

Another AS0 replied "we need federal funds for housing, food, and food for the needy. AIDS/HIV victims need help with medications and health care. We do not have any funds. It is much needed to have a designated area apartment with special attention to HIV victims. A total health care program is needed. Please help."

A lack of awareness of Tile II programs and services was the second most frequently mentioned problem (4 **ASOs).** An AS0 in Alabama replied that it is difficult for individuals living with HIV to access Title II services because of a lack of awareness of the programs. "HIV infected individuals need to know where, when, and how these services can be utilized." Given the benefits of the drug assistance programs and the other services funded by Title II of the CARE Act, lack of awareness of these programs by people with HIV illness is a problem that needs to be addressed.

Other problems with Tile **II programs that were mentioned** by only one AS0 in the survey process are: accessibility of services; burnout for people involved with HIV services; fragmented care - too many agencies/different eligibility criteria; immigrants have access problems; limited choice of physicians/medical practices; limited coverage encourages funding "deserving" patients; limited drug formulary; no inpatient coverage; must be a client and get award through an **ASO;** privacy concerns/fears; timeliness of awards; and transportation problems.

Survey Results: Title I of the Ryan White CARE Act

Effective Services Covered

Table 8-3 presents the health and care-related services funded by Title I of the Ryan White CARE Act that the ASOs identified as most effective at meeting the needs of people with HIV illness. The effective services listed in Table 8-3 are a blend of both health care and social services. Most of the beneficial social services listed in Table 8-3 are not available from the traditional state Medicaid programs but can be provided to eligible people with AIDS through the Medicaid home and community-based care waiver programs.

Other effective services covered by Title I programs that were mentioned by only one AS0 in the survey process are: attendant care; early intervention skills building (living with HIV); residential care facility; and substance abuse treatment. In addition, one AS0 responded that the Title I program covers health care for people not eligible for Medicaid or other public programs.

Effective Services Not Covered

The questionnaire asked for a listing of any health or care-related services that programs funded by Title I of the CARE Act do not cover that would be effective at meeting the needs of people with HIV illness. As no health or care-related service was mentioned more than once, the responses from the ASOs are not listed in Table 8-3. instead, the responses are presented in the text. Effective services not covered by Title I programs that were mentioned by only one AS0 in the survey process are: child care; emotional and practical support; insurance continuation for people with HIV (without a diagnosis of AIDS); legal services; limited mental health funding; and most medical needs not met with Title I funding are covered by Title II programs. In addition,

Table 8-3: **Title I** of the Ryan Whiie CARE Act

Effective Health and Care-Related Services for People with AIDS

Rank	
1.	food and nutrition **(4)**
1.	**social** services, continuum of care/community services referral/benefits counseling (4)
3.	case management **(3)**
3.	prescription drugs/medications **(3)**
3.	primary care **(3)**
6.	dental care **(2)**
6.	emergency assistance/financial assistance (2)
6.	housing (2)
6.	mental health services (2)
6.	transportation services (2)

Note: the number in parentheses following each health or care-related service is the number of **ASOs** mentioning the service.

an AS0 responded that the Title I program in its services area does not cover support services for family and friends. This AS0 added "often we encounter family that feels 'left out' because services embrace the HIV infected person but not the [other] affected person."

Problems with the Title I Programs

The questionnaire asked the ASOs to mention any problems that people with HIV have with the Title I program in their service area. As no problem was mentioned more than once, the responses from the ASOs are not listed in Table 8-3.

The problems with Title I that were mentioned only once in the survey process are: different level of services offered to people with HIV compared to the level of services offered to people with AIDS; difficult to access funding; inefficient system - "i.e., pay more for case manager to get drugs for a client than the drugs are worth"; inequities in coverage of clients by state in a bi-state EMA; large county - difficult to provide services where patients/clients live; not enough funding; Tile I planning council is cumbersome; and understanding and complying with eligibility rules/documentation. In addition, an AS0 reported that "the most common problem [in their service area] is the transportation issue. Transit systems are limiting in this city and generally, a person living on disability (eligible for services) can not afford a vehicle, the insurance, maintenance, and cost of petrol. Therefore. services are not attended."

Survey Results - The Medicare Program

Effective Services Covered

The questionnaire asked the ASOs to "list the health and care-related services covered by the Medicare program that are most effective at meeting the needs of people with HIV illness". Table 8-4 presents all the responses from the ASOs, with

Table 84: The Medicare Program

A.) Effective Health and Care-Related Services for People with AIDS

Rank

1. primary care/primary physician (17)
2. inpatient hospital care (16)
3. outpatient hospital services (9)
4. lab services/diagnostic testing (7)
5. home health care (4)
6. durable medical equipment (2)
6. hospice (2)
6. medical supplies (2)
9. flu/pneumonia shots (1)
9. skilled nursing home care (1)

B.) Effective Health and Care-Related Services for People with AIDS Not Covered

1. prescription drugs (17)
2. dental services (2)
2. transportation (2)
4. assisted living facilities (1)
4. eye exams (1)
4. I.V. medications at home (1)
4. physician participation (1)
4. psycho-social services (1)

C. Problems with Medicare Encountered by People with AIDS

1. prescription drugs not covered (6)
2. eligibility process/length of time for eligibility (5)
3. complexity of Medicare coverage of services (3)
3. cost sharing requirements for Medicare patient is more than many can pay (3)
5. slow and low payments to providers cause reluctance to participate (2)
6. access to services (1)
6. difficult/cumbersome for Medicare patients to use Medicaid spend down to qualify for Medicaid coverage of prescription drugs (1)
6. difficult for people with HIV (without AIDS) to qualify for Medicare (1)
6. HMOs (most comprehensive Medicare-covered care available) typically unwilling to accept people with AIDS (1)
6. lack of support services covered (Medicare is a medical program) (1)
6. Medicare criteria for home-based services are strict - few HIV patients meet these criteria (1)
6. Medicare (Part B) premiums cost more than most can afford (1)
6. private Medicare insurance supplements (Medigap policies) provide inadequate prescription drug coverage and are expensive (1)

Note: the number in parentheses following each health or care-related service is the number of ASOs mentioning the service.

physician services and inpatient hospital care the two most frequently mentioned services covered by Medicare that are most effective at meeting the care needs of people with HIV illness.

Effective Services Not Covered

The questionnaire asked the ASOs to "list any health and care-related services that the Medicare program does not offer that would be effective at meeting the needs of people with HIV illness". As Table 8-4 documents, the ASOs overwhelmingly responded (17 ASOs) that prescription drug coverage was a health service needed by people with HIV illness that the Medicare program does not cover. One AS0 responded that if Medicare was "the only health insurance a disabled person has, lack of access to medications is a significant problem." Noting that Medicare does not cover prescription drugs, an AS0 in Tennessee replied that people on Medicare use Medicaid spend down to qualify for Medicaid coverage of prescription drugs. However, "spend down is a problem for people with limited incomes and it is very cumbersome." Given the effectiveness of the combination drug therapies in combatting the progression of HIV disease, the lack of Medicare reimbursement of prescription drugs is a major weakness in Medicare coverage for people with HIV illness.

Problems with Medicare

The questionnaire the ASOs to "mention any problems or difficulties that people with HIV illness" have with the Medicare program. Table 8-4 presents all the responses from the ASOs. Again, the lack of prescription drug coverage by Medicare was the most frequently mentioned response. The eligibility process and the length of time for eligibility was the second most frequently mentioned problem. For a person

with HIV to become eligible for Medicare requires meeting eligibility criteria for Social Security Disability Insurance, including disability status (similar to Medicaid, people with AIDS have presumptive disability), sufficient work-related history, and a 29-month waitingperiod (5 months from disability status for Social Security Disability Insurance payment to begin, then 24 additional months for Medicare coverage to begin).[25] In addition, an AS0 in Alabama replied that "just because an individual is HIV positive does not mean that they qualify for Medicare benefits. A HIV infected individual must have a recognized, AIDS-defining illness to [meet the] disability classification." An Iowa AS0 reported that "many of our clients do not understand how Medicare works (what is covered and what is not) and often confuse Medicaid and Medicare. Also, some of our clients do not- qualify [for Medicare] because they have not been determined disabled or have not been on SSDI for 24 months."

A local government AS0 replied that people with HIV illness in their service area have problems with the Medicare program because "Medicare is a medical program. Therefore, supportive services required by a person with HIV need to be funded by other sources." An AS0 in Florida, however, noted that people with HIV illness can have problems receiving Medicare coverage of medical care services. This Florida AS0 reported that "the [Medicare] criteria for home-based services such as nursing and personal care is very strict. The only way that someone can be covered for these services is if they were just released from a hospital after surgery or are bed bound. Few of the HIV patients are able **to be covered** due to" these strict Medicare criteria.

Medicare cost sharing requirements were also mentioned by three ASOs as a problem that people with HIV confront. For example, a Medicare patient is required to pay a $100 deductible for physician services, as well as 20 percent cost sharing on

physician bills after the deductible requirement has been met. An AS0 in Nebraska noted that "20 percent is more than most can pay and Medicare [Part B] premiums are more than most can afford."

Summary and Conclusion

Public programs are the primary payers for the health and care-related services provided to people with HIV. The coverage, payment, and utilization policies implemented by these public programs affect the care that people with HIV receive. ASOs were surveyed to identify effective services covered, and effective services that are not covered, by these public payers of HIV-related care, as well as identify problems that people with HIV illness have with these programs.

As Table 8-l illustrates, the state Medicaid programs cover a range of health services that meet the needs of people with HIV, with prescription drug coverage mentioned most frequently by the ASOs. However, a number of states place restrictive utilization limits on these health services (for example, three prescriptions per month), often below the levels needed by people with HIV illness. Table 8-l also presents effective health and care-related services that the state Medicaid programs do not cover. All of these services can be provided with the Medicaid home and community-based care waiver programs for people with AIDS/HIV and for the elderly and disabled (people with AIDS can access this programs due to their disability status)? Expanded use of these waiver programs would allow the state Medicaid programs to target effective health and care-related services to people with HIV illness. In addition, due to more generous income eligibility standards, it is easier for people with HIV to qualify for these waiver services than for traditional Medicaid coverage?

Table 8-2 presents effective health and care-related services provided to people with HIV that are funded by Title II of the Ryan White CARE Act. In addition to prescription drugs and physician services, the Title II programs offer support-related services such as food and nutrition, transportation, alternative therapies, mental health and support groups, adult and child day care, and legal services. Limited funding for Title II programs was the problem most frequently identified by the ASOs. A number of ASOs mentioned a lack of awareness of Title II programs as a problem for people with HIV illness.

As Table 8-3 summarizes, the ASOs identified a blend of both health care and social services funded by Title I of the Ryan White CARE Act as most effective at meeting the needs of people with HIV illness. One AS0 responded that the Tile I program in its service area does not cover support services for family and friends of people with HIV disease, with these people feeling "left out." Another AS0 reported the lack of transportation to care results in the loss of care.

As Table 8-4 presents, the Medicare program covers a range of health services necessary for the treatment of acute illness, except for prescription drugs. Given the success of the combination drug therapies in combatting the progression of HIV disease, the ASOs identified the lack of Medicare coverage of prescription drugs as a major problem for people with HIV illness. One AS0 responded that if Medicare was "the only health insurance a disabled person has, lack of access to medications is a significant problem." Another AS0 noted that given the focus of Medicare coverage on acute care/medical care, the lack of Medicare coverage of support services is a problem for people with HIV disease. The length of time for Medicare eligibility (29

months) is a severe problem for people with HIV illness. Medicare cost sharing responsibilities can be more than most people with AIDS can afford.

One AS0 responded that the Title II programs need to address the concerns of people who may recover from HIV-related disability with job and re-education programs. Given the success of the combination drug therapies in combatting the progression of HIV disease, all public programs covering HIV-related care, not just the CARE Act programs, will need to address the health and care-related needs of people who recover from HIV-related disability. If people recover from HIV-related disability, will they lose their disability status? This disability status, for example, is a key element of eligibility for Medicaid coverage. Without this coverage, will they still have access to the combination drug therapies and other health and care-related services that led to their recovery? The eligibility of people who recover from HIV-related disability for public programs will become an increasingly important issue in the near future as new developments in drug therapies and other treatments combat the progression of HIV disease.

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Chapter 9
Compliance with TB Drug Regimens: Incentives and Enablers Offered by Public Health Departments'

Introduction

From 1952 to 1985 the annual incidence of tuberculosis (TB) in the United States fell from 56 cases to 9 cases per 100,00 population, or about a 5 percent decrease per year.' The consistent annual decline of the incidence of TB in the United States ended in the mid-1980s, increasing from 9.1 TB cases per 100,000 population in 1988 to 10.5 cases per 100,000 population in 1992.[2] This trend in the United States of the increasing incidence of TB was reversed in 1993, with the annual incidence of TB falling to 9.8 cases per 100,000 population in 1993, to 9.4 cases per 100,000 population in 1994, and 8.7 cases per 100,000 population in 1995.[3] The resurgence of TB in the late 1980s and early 1990s, however, underscores the importance of developing and implementing effective approaches to control and treat this communicable disease. The purpose of this research is to present the incentives and enablers implemented by state and local health departments in each of the 50 states and the District of Columbia to encourage TB patients to comply with TB drug regimens.

Methodology

To identify these incentives and enablers, a questionnaire was mailed to the directors of the state health departments in each state and the District of Columbia during May, 1995. (In almost all cases, the questionnaires were completed and

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[a]This research is published in the AMERICAN JOURNAL OF PUBLIC HEALTH, Vol. 87, No. 12, 1997.

returned by administrators of the states' TB control programs.) By August, 1995 all 50 states and the District of Columbia returned completed questionnaires. The questionnaire provided the following list of incentives and enablers, with a request to circle any that apply: free meals; free clothing; free transportation to treatment; cash (if yes, how much money); and "other effective incentives (please describe)." Tables summarizing the results of the survey were mailed to the health departments for verifications and updates in October, 1995.

Treatment Incentives and Enablers

An ad hoc committee of the Scientific Assembly on Microbiology Tuberculosis and Pulmonary Infections suggests that the use of incentives and enablers can help encourage TB patients to comply with TB drug regimens.[4] Among the incentives identified as successful are food and clothing, with bus tokens and baby-sitting services mentioned as enablers. Food coupons and cash have also been suggested as incentives to encourage compliance with drug regimens.[5 6] The survey of the directors of the state health departments asked if state or local health departments offered TB patients incentives to comply with TB drug regimens.

As Table 9-1 illustrates, public health departments in most states offered free meals, free clothing, and free transportation to treatment as incentives or enablers to encourage TB patients to comply with TB drug regimens. Most states reported that public health departments in their states did not provide free baby-sitting or day care nor did they provide cash payments to encourage compliance with drug regimens. Among other incentives mentioned by the state health departments as effective were: housing and gas vouchers; grocery store vouchers; housing for homeless TB patients; patient advocacy and assistance with social services; personal items and toiletries;

Table 9-1
Incentives to TB Patients to Comply with TB Drug Regimens
(1995)

	Do State or Local Health Departments in Your State Use the Following Incentives to Encourage TB Patients to Comply with TB Drug Regimens:					
	Free Meals?	Free Clothing?	Free Transportation to Treatment?	Free Baby-sitting or Day Care?	Cash (and the amount provided)?	Other Effective Incentives?
Alabama	yes	yes	yes	yes	yes (amount varies)	none mentioned
	(The American Lung Association provides an incentive fund to the state-operated Tuberculosis Control Program which pays for these incentives.)					
Alaska	yes	yes	yes	no answer	no	housing and gas vouchers
Arizona	yes	yes	yes	no answer	no answer	groceries, food coupons, hygiene packets
Arkansas	no	no	yes - if needed	no	yes ($2.50)	"tender loving care"
California	yes	Local health departments may offer these incentives; it may vary with jurisdiction.				
Colorado	no	no	no	no	no answer	none mentioned
Connecticut	yes	yes	yes	no	yes (less than $5)	yes
Delaware	yes	no	no	no	no	temporary housing
District of Columbia	yes	no	yes	no	no	none mentioned
Florida	yes (food coupons & nutrition supplements)	no	yes (bus tokens)	no	yes (amount varies) in a few areas	grocery store vouchers
Georgia	yes	yes	yes	no	no	no
Hawaii	no	no	yes	no	no	social services support
Idaho	yes	no	no	no	no	no
Illinois	yes	yes	yes	no	no	none mentioned
Indiana	yes	yes	yes	no	no	none mentioned
Iowa	yes	no	yes	no	no	no
Kansas	("Incentives are offered on a local basis; not able to answer on a statewide level.")					
Kentucky	yes	yes	yes	no	no	housing for homeless TB patients and patient advocacy & assistance accessing social services
Louisiana	yes	yes	yes	no	yes (varies by site)	other incentives may be utilized to motivate patients
Maine	yes	yes	yes	yes	yes ($150 maximum)*	none mentioned
	("DOT on select, high risk patients.")					
Maryland	yes	yes	yes	no	no	no
	("particularly in the larger jurisdictions")					
Massachusetts	yes	yes	yes	no	yes (varies with client needs and patient contract)	"Incentive program is designed and tailored to meet whatever can be identified as the patient's greatest need. It is individualized and many,many different types of incentives are possible."
Michigan	yes	yes	yes	no	yes (amount varies)	personal items, such as soap, etc.
Minnesota	yes	no	yes	no	yes ($1 for screening at homeless shelters)	"Some incentives offered on a local basis; not able to answer on a statewide level."
Mississippi	yes (as needed)	yes (as needed)	yes	no	yes - for transportation/ fuel costs ($.10 per mile	May pay someone to bring patient to clinic - depends on distance & available transportation
Missouri	yes	yes	yes	no	no	none mentioned

Table 9-1
Incentives to TB Patients to Comply with TB Drug Regimens
(1995)

	Do State or Local Health Departments in Your State Use the Following Incentives to Encourage TB Patients to Comply with TB Drug Regimens:					
	Free Meals?	Free Clothing?	Free Transportation to Treatment?	Free Baby-sitting or Day Care?	Cash (and the amount provided)?	Other Effective Incentives?
Montana	yes (as needed)	yes (as needed)	yes (as needed)	unknown	no	yes**
	(**"County health departments use a variety of incentives/enablers that are tailored to fit the needs of the patient; many times these change throughout the course of therapy (books, food, support groups.")					
Nebraska	yes (at times)	no	yes	no	no	none mentioned
Nevada	yes	no	yes	no	no	yes***
	(***"Food, coffee, fruit, and condoms are available in the TB clinic waiting room in Las Vegas. Patients also are assisted with residential care if they are homeless."					
New Hampshir	yes	no	no	no	no	none mentioned
New Jersey	yes~	yes~	yes~	no	no	food vouchers, food supplements (Sustecal)~
	~varies in each clinic					
New Mexico	no	no	no	no	no	no
New York	yes	yes	yes	no answer	no	individualized needs identified for the patient
North Carolina	yes	yes	yes	yes	yes - usually enough for a meal or a cab	"individualized, per patient need"
North Dakota	yes	no	yes	uncertain	no	toys or treats for children
Ohio	yes	yes	yes	yes	yes - $40 per month	individualized needs identified for the patient
Oklahoma	no	no	yes	no	no	"Threat of court-ordered confinement if non-compliant with treatment (active cases only)."
Oregon	yes	yes	yes	yes	yes $10 to $20 per wee	Tickets to sporting events, diaper service, sports equipment, vouchers for fast food, bus passes, etc.
Pennsylvania	yes	yes	yes	yes	no	"We try to provide whatever it takes to assure patient compliance with therapy."
Rhode Island	yes	yes	yes	no	yes - $5 per dose~~	"Almost anything you can imagine."
	~~This is used as a last resort, but it does work for the most recalcitrant patients.					
South Carolina	yes	yes	yes	yes	es - it varies, dependin on the purpose	"Whatever it takes to motivate the patient."
South Dakota	no	no	no	no	no	no
Tennessee	yes	yes	yes	no	no	"Everything from birthday cards to car batteries."
Texas	no answer	no answer	yes	no answer	no answer	rent assistance, medical equipment (oxygen concentrator)
Utah	yes	yes	yes	no	yes - $10 per week	aluminum cans, housing, bus tokens/passes, clothing, and sleeping bags
Vermont	not available	not available	not available	not available	not available	not available
Virginia	yes	yes	yes	no	no	"Housing in exchange for compliance with DOT for homeless TB patients."
Washington	yes	yes	yes	no	no	"Things for children of patients."
West Virginia	no	no	no	no	no	no
Wisconsin	no	yes (only in Milwaukee)	yes	no	no	individual patient need~~~
	~~"County health departments use a variety of incentives/enablers that are tailored to fit the needs of the patient; these incentives/enablers may change throughout the course of therapy."					
Wyoming	no	no	no	no	no	no

Source: a 1995 survey of the state health departments.
This research was funded by a grant from the Health Care Financing Administration, U.S. Department of Health and Human Services.

toys or treats for children; tickets for sporting events; diaper services; medical equipment; and "everything from birthday cards to batteries." A number of states responded that their public health departments used a variety of incentives and enablers designed to meet the individual needs of TB patients to encourage compliance with drug therapies. As the Department of Public Health in Massachusetts replied, the incentive program is "designed and tailored to meet whatever can be identified as the patients' greatest need. It is individualized and many, many different types of incentives are possible."

Summary and Conclusions

The results of the survey conducted for this study indicate that public health departments in almost all states are implementing the incentives and enablers that TB experts advocate to encourage patients to comply with drug regimens in efforts to control this disease. The implementation of these TB incentives, along with public health screening and treatment programs combined with dramatically increased federal funding for TB control during federal fiscal year 1993, may help to explain why the incidence of TB resumed its long term decline in the United States in 1993 after a decade of resurgence. The resurgence of TB during the 1980s is attributable, at least in part, to inadequate public funding for TB control by the federal, state, and local governments.' In 1981 Congress created a categorical grant program to state and local governments for TB control with section 317 of the Public Health Service Act.[8] However, this grant program was not funded at authorized levels until 1992. For example, the program was authorized at $9,000,000 in federal fiscal year 1982 but only $1 ,OOO,OOO was appropriated; in federal fiscal year 1991 $36,000,000 was authorized but only $9,109,000 was appropriated. During federal fiscal years 1992 and 1993

$15,321,000 and $73,630,000 was appropriated respectively, with authorization in both years set at such sums as necessary.' The resurgence of TB in the United States during the 1980s illustrates that the danger of TB to the nation's health is a constant threat.

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Chapter 10
Tuberculosis and HIV Infection: Utilization of Public Programs to Fund Treatment Services[a]

Introduction

The annual incidence of tuberculosis (TB) in the United States fell from 56 cases per 100,000 population in 1952 to 9 cases per 100,00 population during 1985, or about a 5 percent decrease per year.[1] The consistent annual decline of the incidence of TB in the United States ended in the mid-1980s, with rates increasing from 9.1 TB cases per 100,000 population in 1988 to 10.5 cases per 100,000 population by 1992.[2] This trend of the increasing incidence of TB in the United States was reversed in 1993, with the annual incidence of TB falling to 9.8 cases per 100,000 population in 1993, to 9.4 cases per 100,000 population in 1994, and to 8.7 cases per 100,000 population in 1995.[3] The recent resurgence of TB, however, underscores the importance of developing and implementing effective public health programs and policies to combat this communicable disease.

TB control experts have recommended that public health departments develop and administer a number of policies and programs to eliminate TB. For example, the Advisory Council for the Elimination of TB recommends that public health departments implement TB identification, screening, and reporting programs.[4] Directly observed therapy programs[5,6,7,8] and nursing case management[9] are advocated as important public health approaches to the control of TB. The purpose of this article is to present treatment approaches that state and local health departments have

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developed and implemented in each of the 50 states and the District of Columbia to combat TB. Given the financial pressures confronting health departments in their efforts to control TB, this research also presents how public health departments are utilizing a number of different public programs to pay for needed TB-related care.

TB and AIDS

The increase in the rates of TB cases that began in the mid-1980s has been mostly confined to urban areas with high rates of HIV infection." Seroprevalence surveys in TB clinics confirm a high rate of HIV infection among people with TB and matching TB and AIDS registries demonstrates a strong association between the two diseases." [12 13] During 1990 54.2 percent of people between 20 and 49 years of age who died with TB also had AIDS listed on their death certificates.[14] More than 1 in 10 people with AIDS in New York and about 1 in 14 people with AIDS in Illinois had active TB in 1993.[15] TB is probably the only HIV-related disease that can be transmitted to someone who is not infected with HIV.[16] The increasing incidence of HIV infection and the prevalence of TB in low-income and disenfranchised people creates a public health threat." The incidence of TB and HIV among low-income people increases the role of public programs in funding the health services necessary to treat TB and HIV-related illness. This article will examine the role of public programs in funding TB-related health services.

Methodology

To identify how public health programs are treating TB, and utilizing public programs to help pay for this care, a questionnaire was mailed to the directors of the state health departments in each state and the District of Columbia during May, 1995. (In almost all cases, the questionnaires were completed. and returned by

administrators of the states' TB control programs.) By August, 1995 all 50 states and the District of Columbia returned completed questionnaires which included questions on TB treatment policies and public funding sources for TB-related care. Tables summarizing the results of the survey were mailed to the health departments for verifications and updates in October, 1995.

TB Treatment Policies

The availability of TB treatment services and transportation to care are frequently problems for people in high incidence and socioeconomically disadvantaged areas." The Advisory Council for the Elimination of Tuberculosis recommends that: TB treatment services and related transportation should be available at no cost to patients; special treatment housing centers should be established for homeless people at risk for TB; directly observed therapy (DOT) programs be considered for all TB patients; and outreach workers be used as a link between the TB patient and health professionals. [19]

DOT programs, which involve watching patients take each dose of medicine, have been successful in the treatment and control of **TB.**[20] Some have argued that "sound public health practice dictates" the use of DOT during TB treatment.*' Between 1992 and 1994 the number of reported TB cases in New York City declined by 21 percent, with DOT an important contributor to this **decline.**[22] Similarly, there was a decline in the incidence of TB in Baltimore during the 1980s after implementation of a DOT program?

The survey of the directors of state health departments asked if state or local health departments in their states provide a range of health care services at no charge to TB patients. The questionnaire provided a list of services, with a request to circle

any that apply. The services listed on the questionnaire were: TB treatment services; TB drug therapies; transportation to health services; special treatment housing centers; directly observed therapy programs; outreach workers; and "other health services (please describe)." The responses from each state and the District of Columbia are presented in Table 10-l. All states reported providing free TB drug therapies and most states provided free TB treatment services (although some states reported a sliding scale fee or nominal fees for these services). In addition, all states reported the use of DOT programs.

According to the survey responses, public health departments in most states utilized outreach workers in the effort to treat and control TB. These outreach workers can be of the same ethnic or cultural background as the patient and can establish a stronger relationship with the TB patient than the more traditional health professional.[24] These outreach workers act as extensions of health providers by locating TB patients, helping patients with appointments, encouraging adherence to treatment, and delivering medications and observing that proper doses are taken?

Most states provided transportation to health care, while most states responded that they did not provide special treatment housing centers. Among other services that public health departments provided in the treatment of TB patients were: coordination of services with other agencies; sputum collection; inpatient respiratory isolation if needed; medical monitoring for TB treatment; incentives to comply with treatment; inpatient diagnostic and outpatient diagnostic and management services; HIV testing and counseling; laboratory and X-ray services; isolation housing for contagious homeless people; and case management services.

Table 10-1
TB-Related Health Services
(1995)

	Do State or Local Health Departments in Your State Provide the Following Health Services at no Charge to People with TB:							Do State or Local Health Departments in Your State Use Nursing Case Management to Control and Treat TB, Assigning One Person to Each TB Case?
	TB Treatment Services?	TB Drug Therapies?	Transportation to Health Care?	Special Treatment Housing Centers?	Directly Observed Therapy Programs?	Outreach Workers?	Other Health Services?	
Alabama	yes	yes	yes	yes	yes	yes	none mentioned	yes
Alaska	no	yes	case by case	no	yes	yes	incentives	no
Arizona	yes	yes	yes	yes	yes	yes	none mentioned	yes
Arkansas	yes	yes	yes	housing provided in motels if needed	yes	yes	no	no
California	yes	yes	yes	yes	yes	yes	none mentioned	yes
	(Local health departments may offer these services. It depends on the jurisdiction -- some do, some do not.)							
Colorado	yes	yes	yes	yes	yes	yes	none mentioned	no
				(1 local health department)				
Connecticut	yes	yes	yes	no	yes	yes	yes	yes
Delaware	yes	yes	no	no*	yes	yes	coordination of services with other agencies	yes
			* health departments in Delaware do pay for temporary housing that meets standards for single occupancy dwellings with individual ventilation systems					
District of Columbia	yes	yes	yes	no	yes	yes	none mentioned	yes
Florida	yes (minimal fee charged; waive if patient cannot pay.)	yes	yes (in some counties)	yes	yes	yes	yes	yes (in some counties)
Georgia	yes	yes	some	yes	yes	yes	some	yes
Hawaii	yes	yes	occasionally	yes	yes	yes	none mentioned	yes
Idaho	yes	yes	no	no	yes	yes	none mentioned	yes
Illinois	yes	yes	yes	no	yes	yes	none mentioned	yes
Indiana	no	yes	no	no	yes	yes	none mentioned	yes
Iowa	**	yes	no	no	yes	yes	sputum collection	yes
	(**State and local health departments in Iowa do not provide x-ray services, physical exams, or TB clinics. However, local health departments do conduct skin testing, sputum specimen collecting, and conduct oral interviews of TB suspects, TB patients, and people on preventive therapy.							
Kansas	yes	yes	yes	no	yes	yes	none mentioned	in some cases
Kentucky	yes	yes	yes	yes	yes	yes	inpatient respiratory isolation as needed	yes (Policies may vary with local health depts.)
	(Patients are charged a nominal fee for these services, which is waived if a patient is unable to pay.)							
Louisiana	yes	yes	yes	no	yes	yes	no	yes - outreach workers
Maine	yes	yes	no	no	yes	yes	no	yes
Maryland	yes	yes	sometimes	no, but beginning to provide housing in motels for some	yes	yes	medical monitoring for TB treatment	yes
Massachusetts	yes	yes	no, not routine	no	yes	yes	incentives/ enablers	yes
Michigan	yes	yes	"a little"	no	yes	yes	none mentioned	yes
Minnesota	no***	yes	yes	no	yes	yes	***	yes
	***Two local health departments have public clinics. Local health departments provide direct services, but have no budget for clinic or hospital costs. The services provided depend on the patient and run the gamut."							
Mississippi	yes	yes	yes	individual housing as needed but not at centers	yes	yes	inpatient diagnostic & outpatient diagnostic/mgt. services	yes
Missouri	yes	yes	yes	no	yes	yes	no	yes

Table 10-1
TB-Related Health Services
(1995)

	Do State or Local Health Departments in Your State Provide the Following Health Services at no Charge to People with TB:							Do State or Local Health Departments in Your State Use Nursing Case Management to Control and Treat TB, Assigning One Person to Each TB Case?
	TB Treatment Services?	TB Drug Therapies?	Transportation to Health Care?	Special Treatment Housing Centers?	Directly Observed Therapy Programs?	Outreach Workers?	Other Health Services?	
Montana	no~	state only	yes	no~	yes	yes	yes	yes
(~if the patient lacks ability to pay, local or state health department will work to cover the costs of physician visits and housing if necessary to complete directly observed therapy treatment plan. These services are provided as needed when no other means are available.)								
Nebraska	yes	yes	yes	no	yes	yes	none mentioned	yes
Nevada	yes	yes	yes	yes	yes	yes	HIV testing/counseling referral to other health care	no
New Hampshir	yes (If financially eligible)	yes	no	no	yes	yes	yes	yes
New Jersey	yes~~	yes	yes	no	yes	yes	diagnostic services~~	yes (some nurse case mgt.; some non-nurse case mgt.)
	(~~varies from clinic to clinic - some charge for services)							
New Mexico	yes	yes	no	no	yes	yes	lab services and X-ray services	yes
New York	yes	yes	yes	yes	yes	yes	none mentioned	yes
North Carolina	yes	yes	yes	yes	yes	yes	diagnostic services	yes
North Dakota	no	yes	yes	no	yes	yes	no	yes
Ohio	yes	yes	yes (partial)	no	yes	yes	no	yes
Oklahoma	yes	yes	yes (limited)	no	yes	no	isolation housing for contagious homeless people	no
Oregon	yes	yes	if necessary	if necessary	yes	yes	none mentioned	yes
	(Local health departments do try to collect third-party payments.)							
Pennsylvania	yes	yes	yes (some)	yes	yes	yes	none mentioned	no
Rhode Island	yes	yes	yes	no	yes	yes	none mentioned	yes
South Carolina	yes	yes	yes	yes	yes	yes	hospitalization	yes
South Dakota	yes	yes	no	no	yes	yes	no	no
Tennessee	yes	yes	yes	yes	yes	yes	yes	yes
Texas	yes	yes	yes	yes	yes	yes	none mentioned	yes
Utah	yes	yes	limited	yes	yes	yes	none mentioned	yes
Vermont	yes	yes	no answer	no answer	yes	yes	none mentioned	yes
Virginia	yes~~~~ ~~~sliding scale fees	yes~~~~	yes	individual housing for homeless with TB	yes	yes	acute care diagnostic/case mgmt. services	yes
Washington	yes (sliding scale fees; usually charge but cannot deny services if they do not pay)	yes	yes	no, but 1 center is coming	yes	yes	HIV testing and counseling referral	no
West Virginia	yes	yes	no	no	yes (limited)	yes (limited)	no	yes
Wisconsin	yes, but only in Milwaukee	yes	yes	no	yes	no	no	yes
Wyoming	no for hospital care & doctor office visits	yes	no	no	yes	no	yes	95%

Source: Robert J. Buchanan, Ph.D., Department of Community Health, University of Illinois, a 1995 survey of the state health departments. This research was funded by a grant from the Health Care Financing Administration, U.S. Department of Health and Human Services (grant # 18-P-90286/5-01).

Nursing case management has been advocated as a comprehensive approach to ensure that TB patients complete therapy.= With this case management, one person is assigned to each case of TB. Among the responsibilities of the case manager are: assessment of the patient's health and psychosocial needs; assessment of factors affecting adherence to treatment, access to health care, and cultural or language barriers to care; assignment of people to provide DOT; assignment of outreach workers; monitoring care during treatment; and assisting the TB patient with any necessary support services to ensure compliance with therapy? The questionnaire asked the directors of the state health departments if state or local health departments in their states utilized "nursing case management to control and treat TB, assigning one person to each case of TB?" As Table 10-I documents, public health departments in most states utilized these nursing case managers to control and treat TB. Many of these treatment-related services for TB can be funded by a number of public programs.

Funding TB Care

The availability of financial resources to treat and prevent TB is a major concern, as the costs for TB treatment increase without appropriate increases in resources to metropolitan health departments.[28] Low incomes, lack of health insurance, and limited access to health care for many people with TB limit their ability to adhere to treatment, with the lack of adherence leading to treatment failure, drug resistance, continuing spread of infection, and death.[29] With many TB patients lacking health insurance and health departments lacking sufficient resources to provide all essential TB-related services, public health officials should utilize Medicare, Medicaid, and other sources of public funding for TB care?

The questionnaire asked the directors of the state health departments if state or local health departments in their state evaluated people with TB for eligibility for Medicaid, Medicare, and programs funded by Title I and II of the Ryan White CARE Act during 1995. As Table 10-2 illustrates, health departments in many states did not evaluate TB patients for eligibility for these public programs, although Connecticut and Minnesota reported that private physicians do this evaluation. Mississippi responded that local health department staff "as a routine - not policy" refer patients to agencies that can assist TB patients with the eligibility process for these programs. An important role for case managers in the treatment of TB can be to assist patients with identifying public programs to cover their care and to guide them through the application process.[31] 32 Utah replied to the survey that a Medicaid nurse case manager was hired to evaluate TB patients for Medicaid eligibility.

The Ryan White CARE Act Programs

Given the susceptibility of people with HIV infection to TB, programs funded by the Ryan White CARE Act can provide health services to people with HIV who are also infected with TB. Title I of the CARE Act provides funds to eligible metropolitan areas (EMAs) with the largest number of AIDS cases. EMAs are required by the CARE Act to provide a continuum of outpatient and ambulatory health and support services to people with HIV, including case management services and comprehensive treatment.= Title II of the CARE Act allocates funds to the states to provide HIV-related medical and support services, allowing the states to implement HIV consortia programs, HIV/AIDS drug assistance programs, home and community-based care programs, and health insurance continuation programs?

Table **10-2**
Funding for TB Care
(1995)

	Do State or Local Health Departments in Your State Evaluate People with TB for Eligibility for the Following Programs:			
	Medicaid	Medicare	Title I - Ryan White*	Title II - Ryan White
Alabama	no	no	No Title I funds during 1995	no
Alaska	no	no	No Title I funds during 1995	no
Arizona	no	no	no	no
Arkansas	yes	yes	No Title I funds during 1995	no
California	yes	yes	yes	yes
Colorado	yes	yes	yes	yes
Connecticut	yes	yes	yes	yes
	"The state health department is required by law to pay for all TB care and treatment. Since TB care and treatment in Connecticut is delivered by private physicians, those physicians must evaluate patients for all third party payers and petition third party payers for payment before the state health department can pay for care/treatment."			
Delaware	yes	yes	No Title I funds during 1995	yes
District of Columbia	yes	yes	yes	yes
Florida	yes	yes	yes	yes
Georgia	no	no	yes	yes
Hawaii	no	no	No Title I funds during 1995	no
Idaho	no	no	No Title I funds during 1995	no
Illinois	no	no	no	no
Indiana	no	no	No Title I funds during 1995	no
Iowa	no	no	No Title I funds during 1995	no
Kansas	yes	yes	yes	yes
Kentucky	yes	yes	No Title I funds during 1995	yes
Louisiana	yes	no	no	no
Maine	yes	yes	No Title I funds during 1995	no
Maryland	no	no	no	no
Massachusetts	under consideration, currently being piloted	no	yes where applicable	yes where applicable
Michigan	yes	yes	yes (where primary M.D.s are available)	no
Minnesota	yes	no	No Title I funds during 1995	yes, some (metro)
	"The state TB program does not evaluate for eligibility in any of these programs. [Local health departments may, as indicated.] ... The majority of TB patients in Minnesota are treated by private physicians who may evaluate eligibility for these programs as appropriate.")			
Miippi	no	no	No Tiie I funds during 1995	yes
	"We do not evaluate for eligibility. However, we do ask dients about insurance coverage and bill for eligible service. If a dient does not have coverage and appears to be eligible, as a routine - not policy, local staff will refer patients to other agencies that would be able to further assist the patient/client in determining eligibility."			
Missouri	yes	yes	yes	yes

Table 10-2
Funding for TB Care
(1995)

	Do State or Local Health Departments in Your State Evaluate People with TB for Eligibility for the Following Programs:			
	Medicaid	Medicare	Title I - Ryan White'	Tie II - Ryan White
Montana	Yes	Yes	No Title I funds during 1995	yes
Nebraska	yes	yes	No Tiie I funds during 1995	yes
Nevada	yes	no	No Tii I funds during 1995	yes
New Hampshir	Yes	Yes	No Tii I funds during 1995	Yes
New Jersey	yes**	yes**	Yes"	yes**
	** not routinely, but varies from dinic to clinic			
New Mexico	no	no	No Title I funds during 1995	no
New York	yes	no	no	no
North Carolina	yes	yes	No Title I funds during 1995	no
North Dakota	Yes	yes	No Title I funds during 1995	yes
Ohio	yes	yes	yes (the Cleveland area began receiving Title I -funds in 1996)	yes
Oklahoma	Yes	no	No Title I funds during 1995	Yes
Oregon	Yes	yes	Yes	yes
Pennsylvania	Yes	no	not applicable	not applicable
Rhode Island	yes but inconsistently	yes but inconsistent&	No Title I funds during 1995	no
South Carolina	yes	Yes	No Title I funds during 1995	Yes
South Dakota	yes	Yes	No Title I funds during 1995	yes
Tennessee	Yes	no	No Title I funds during 1995	no answer
Texas	yes	no answer	no answer	Yes
Utah	yes***	not routinely	No Tiie I funds during 1995	no answer
	*** "We hired a Medicaid nurse case manager to evaluate infected and diseased TB patients."			
Vermont	ves	no answer	No Title I funds during 1995	no answer
Virginia	Yes	no	yes	yes
Washington	Yes	yes	Yes	y e s
West Virginia	no	no	No Title I funds during 1995	no
Wisconsin	yes	no	No Title I funds during 1995	no
Wyoming	yes	yes and no~	No Title I funds during 1995	Yes
	-"Some county health departments are Medicare certified and bill Medicare. Some do not"			

*Title I programs funded by the Ryan White CARE Act are available only in large metropolitan areas with high incidences of AIDS.
Several states are not eligible for Tiie I funds. States not receiving Title I funds during 1995 are identified with "Fact Sheet",.
Office of Communications, Health Resources and Services Administration, US. Department of Health and Human Services, Rockville, MD.

Source: Robert J. Buchanan, Ph.D., Department of Community Health, University of Illinois, a 1995 survey of the state health departments. This research was funded by a grant from the Health Care Financing Administration, U.S. Department of Health and Human Services (grant # 1 S-P-90286/5-01).

HIV consortia funded by Title II of the CARE Act can provide a number of the TB-related services listed in Table 10-1 to eligible people with HIV.[35] For example, HIV consortia in many states provide case management services, primary medical care, personal care, transportation services, nutritional services, and housing assistance. The Title II program also funds HIV/AIDS drug assistance programs (HADAPs).[36] Depending upon the availability of funding, these HADAPs may provide TB-related medications to eligible people infected with TB and HIV (see Table 10-3). In addition, home and community-based care (H&CBC) programs funded by Title II can provide a range of TB-related services to eligible people with HIV and TB.[37] These Title II H&CBC programs, which are implemented in a number of states, fund a range of services, among these beneficial to people with HIV and TB are: durable medical equipment, in-home diagnostic testing, comprehensive nurse case management, attendant care, day treatment services, personal care, and housing assistance.

The **Medicare Program**

In addition to the elderly, Medicare coverage is potentially available to the disabled if they meet certain work-related requirements. For a person with TB to become eligible for Medicare requires meeting eligibility criteria for Social Security Disability Insurance (SSDI), including disability status (similar to Medicaid, people with AIDS have presumptive disability), sufficient work-related history, and a 29-month waiting period (5 months from disability status for SSDI payment to begin, then 24 additional months for Medicare coverage to begin).[38] Although not a major payer of the care needed by people with AIDS who are also infected with TB, the Medicare program can be a source of funding for inpatient treatment for people who are eligible.

One study found that expenditures for inpatient care of patients with TB accounted for 60 percent of TB-related spending? For people who are eligible for benefits, the Medicare program also can cover inpatient and outpatient medical care, as well as the diagnostic, lab, and X-ray services mentioned in Table 10-I. However, the Medicare program does not cover and reimburse outpatient prescription drugs.

The State Medicaid Programs

Financial eligibility requirements for Medicaid vary from state to state, with eligibility potentially available to the elderly, the blind, and the disabled, as well as anyone receiving benefits from the Aid to Families with Dependent Children program? As a result of a ruling by the Social Security Administration, people with a diagnosis of AIDS are presumed to meet the disability standard.[41] In July 1993 the Social Security Administration published a listing of HIV-related conditions that can be used to establish presumptive disability for people infected with HIV but without a diagnosis of AIDS.[42]

The state Medicaid programs must cover and reimburse inpatient and outpatient hospital care, physician services, rural clinic services, laboratory services, and X-ray services for eligible recipients. In addition, the state Medicaid programs have the option to cover prescription medications, clinic services, diagnostic services, screening services, personal care, transportation to health care, case management, and respiratory services? Hence, the Medicaid programs can cover many of the TB-related services listed in Table 10-l. In addition, these Medicaid services can be specifically matched to the care needs of Medicaid recipients infected with TB and HIV. For example, the diagnostic-related group (DRG) payment system for inpatient hospital care implemented by the New York State Medicaid program during 1994 had

numerous DRGs for patients infected with both HIV and TB.[44] Similarly, a number of state Medicaid programs adjust payments to nursing facilities to reflect the higher costs associated with respiratory therapy and isolation for TB.[45]

Home and Community-Based Care Waivers

A number of state Medicaid programs use the home and community-based waiver programs to offer an expanded array of services to Medicaid recipients with AIDS. Section 2176 of the 1981 Omnibus Budget Reconciliation Act gives the Health Care Financing Administration the authority to waive certain federal Medicaid regulations to allow the states to include home and community-based care in their Medicaid coverage, targeted to specific Medicaid recipients such as the elderly or the physically disabled who would otherwise have to be institutionalized? [47] The Omnibus Budget Reconciliation Act of 1985 amended Section 2176 to allow AIDS-specific, Medicaid home and community-based waiver programs.[48] The Medicaid programs can use either the original waiver program to provide special services to Medicaid recipients with AIDS who also have TB through their disability status or the AIDS-specific waiver program. These waiver programs have more generous eligibility requirements and can cover services not included in the regular Medicaid program.[49]

The questionnaire asked the directors of the state health departments if state or local health departments in their state provided care to people with TB who received Medicaid coverage under the home and community-based care waiver programs. As Table 10-3 documents, a number of states reported that Medicaid recipients with TB received services through these waiver programs. The questionnaire also asked the directors to identify any waiver services "that were beneficial to the care and treatment of people with TB," with the responses presented in Table 10-3. Among the services

Table 10-3
Coordination of TB Care with Other Health Programs
(1995)

	Have State or Local Health Departments in Your State Provided Care to People with TB who Receive Medicaid Benefits Utilizing Services Covered Under the Medicaid Home and Community-Based Care Waiver for:			For People with TB Who are Eligible for Medicaid or Ryan White Programs in Your State, do the Prescription Drug Formularies of These Programs Include all FDA-Approved Drugs to Treat TB (Including MDR-TB*)?		
	The Elderly and Disabled?	People with AIDS?	Waiver Services Beneficial to TB Care	Medicaid	itle I - Ryan White*	Title II - Ryan White
Alabama	yes	yes	Lab service and hospitalization	TB Control Program not involved with Medicaid billing	no Title I program	no
Alaska	no answer	no answer	no answer	unknown	unknown	unknown
Arizona	no	no	not applicable	yes	yes	yes
Arkansas	no	no	not applicable	yes	yes	yes
California	yes	yes	case management and support services (food, substance abuse treat-ment, housing, etc.)	no answer	There are 7 Title I areas in the state; do not know if TB drugs on their formularies	no FDA-approved drugs for TB on Title II formulary
Colorado	not available	yes	RN, respiratory therapy, LPN, home health aide, personal care services	yes	no - TB drugs are provided under Medicaid formulary	no - TB drugs are provided under Medicaid formulary
Connecticut	yes	yes	not known	unknown	unknown	unknown
Delaware	yes	yes	independent living	yes	no Title I program	yes
District of Columbia	no	no	not applicable	yes	yes	yes
Florida	no	yes	possibly home health services	yes	no - TB drugs not provided; TB drugs provided with state general revenues	no - TB drugs not provided; TB drugs provided with state general revenues
Georgia	no	yes	some case mgmt. and home health	not applicable	yes	yes
Hawaii	no	no	not applicable	no	no	no
Idaho	no	no	not applicable	yes	no TB drugs covered	no TB drugs covered
Illinois	no	no	not applicable	no TB drugs covered	no TB drugs covered	no TB drugs covered
Indiana	no	no	not applicable	yes	no Title I program	no TB drugs covered
Iowa	no	no	not applicable	state TB program provides TB drugs	no Title I program	3 Title II consortia provide all drugs until they reach fiscal limit; 1 consortium provides no TB drugs
Kansas	do not know	do not know	do not know	health department provides TB drugs	no (some)	no (some)
Kentucky	no	no	not applicable	yes	no Title I program	no - (INH, RIF, EMB, ETH, PZA, or SM not covered)
Louisiana	no	yes	home health	yes	yes	yes
Maine	no	no	not applicable	do not know	no Title I program	no***
Maryland	no	no	not applicable	yes	Title I in Maryland does not cover drug	no - only first line drugs available
Massachusetts	no	no	not applicable	health department provides TB drugs	health department provides TB drugs	health department provides TB drugs
Michigan	do not know	do not know	do not know	yes	not listed	no
Minnesota	yes	do not know	yes	yes	yes	yes
Mississippi	no	no waiver program	not applicable	yes	no Title I program	no
Missouri	yes	yes	medications, physician visits, home health care, case management	yes (as long as manufacturer signs rebate agreement)	yes	yes

Table 10-3
Coordination of TB Care with Other Health Programs
(1995)

	Have State or Local Health Departments in Your State Provided Care to People with TB who Receive Medicaid Benefits Utilizing Services Covered Under the Medicaid Home and Community-Based Care Waiver for:			For People with TB Who are Eligible for Medicaid or Ryan White Programs in Your State, do the Prescription Drug Formularies of These Programs Include all FDA-Approved Drugs to Treat TB (Including MDR-TB*)?		
	The Elderly and Disabled?	People with AIDS?	Waiver Services Beneficial to TB Care	Medicaid	itle I - Ryan White**	Title II - Ryan White
Montana	unknown	unknown	unknown	yes	not applicable	yes
Nebraska	yes	yes	directly observed therapy	yes	yes	yes
Nevada	no	yes	outreach services in the home for TB patients not attending TB clinic	yes	no Title I program	yes
New Hampshir	no	no	not applicable	yes	yes	yes
New Jersey	yes	yes	diagnosis, treatment, and prevention	yes	yes	yes
New Mexico	unknown	yes	case management, private duty nursing, homemaker/personal care	yes	no Title I program	no
New York	yes	yes	no	yes	yes	yes
North Carolina	unknown	unknown	unknown	yes	unknown	unknown
North Dakota	unknown	no	not applicable	state health dept. provides all TB drugs	no Title I program	yes
Ohio	yes	yes	unknown, provided at local level	no	unknown	unknown
Oklahoma	no	no	not applicable	yes	no Title I program	no
Oregon	Oregon Health Plan is used	Oregon Health Plan is used	case management	"The state provides TB drugs."		
Pennsylvania	no	no	not applicable	yes	no Title I program	no Title II drug program~
Rhode Island	no ("although we are trying to establish this program.")	no	not applicable	unknown	no	no
South Carolina	yes	yes	TB services provided free of charge to people with TB infection or disease	yes	TB drugs are provided free by the state health dept.	TB drugs are provided free by the state health dept.
South Dakota	yes	no	no answer	no answer	yes	yes
Tennessee	no	no	not applicable	no - the state does not operate Medicaid, now uses managed care	no	no
Texas	no	no	not applicable	yes	yes	yes
Utah	yes	no	no answer	yes	yes	yes
Vermont	not available	not available	not available	not available	not available	not available
Virginia	no	no	not applicable	yes	yes	yes
Washington	yes	yes	housing and meals	no (no floxin or Cipro)	no (no floxin or Cipro)	no (no floxin or Cipro)
West Virginia	yes	yes	general home health services	yes	yes	yes
Wisconsin	data not available	no	not applicable	yes	no Title I program	no - state general revenues cover TB medications
Wyoming	yes	yes	personal care attendant, lifeline, and home-delivered meals	yes	no Title I program	yes

* MDR-TB is the abbreviation for multi-drug resistant tuberculosis.

**Title I programs funded by the Ryan White CARE Act are available only in large metropolitan areas with high incidences of AIDS. Several states are not eligible for Title I funds.

***The drug assistance program in Maine funded by Title II covered AZT, DDI, DDC, Bactrim/Septra, pentamidine, and fluconazole during 1995. (Source: Robert J. Buchanan, survey of the state Title II programs, 1995.)

~No Title II funds supported the statewide AIDS drug assistance program in Pennsylvania during 1995. (Source: Robert J. Buchanan, survey of the state Title II programs, 1995.)

Source: Robert J. Buchanan, Ph.D., Department of Community Health, University of Illinois, a 1995 survey of the state health departments. This research was funded by a grant from the Health Care Financing Administration, U.S. Department of Health and Human Services (grant # 18-P-90286/5-01).

mentioned were case management, home health and personal care services, respiratory therapy, housing, home-delivered meals, directly observed therapy, and outreach services in the home for TB patients.

Drug Formularies

The questionnaire asked if the drug formularies used by the Medicaid program and programs funded by Title I and Title II of the Ryan White CARE Act "include all FDA-approved prescription drugs used to treat TB, including multi-drug resistant TB?" As Table 10-3 illustrates, most state Medicaid programs cover all these drugs, with a number of states reporting that public health departments cover these TB medications. However, as Table 10-3 also presents, the Title I and Title II programs in many states do not include these TB therapies on their lists of covered medications. Given the encouraging results of the new protease inhibitors in treating HIV infection,[50] and the $12,000 to $15,000 annual cost of these medications per person when used in combination drug therapies,[51] the Ryan White programs will face increasing fiscal pressures and may have to restrict the other drugs on their formularies.

Discussion

After a decade of resurgence, the incidence of TB in the United States resumed its long term decline in 1993, 1994, and 1995. As the resurgence of TB during the 1980s illustrates, however, the threat of this disease to the public's health remains present. Aggravating'and enhancing the threat of TB in the United States has been the emergence of AIDS. The spread of TB among people with AIDS has important public health consequences because TB may be the only AIDS-related disease that can be transmitted to people who are not infected with HIV.[52] With the increasing incidence of AIDS in the United States, public health programs must be maintained

and expanded to control TB to protect the public health and the health of people with AIDS.

The resurgence of TB during the 1980s also is attributable to inadequate public funding for TB control by the federal, state, and local governments? In 1981 Congress created a categorical grant program to state and local governments for TB control with section 317 of the Public Health Service Act.[54] However, this grant program was not funded at authorized levels until 1992. For example, the program was authorized at $9,000,000 in federal fiscal year 1982 but only $1,000,000 was appropriated; in federal fiscal year 1991 $36,000,000 was authorized but only $9,109,000 was appropriated. During federal fiscal years 1992 and 1993 $15,321,000 and $73630,000 was appropriated respectively, with authorization in both years set at such sums as necessary.[55]

Based on the results observed in New York City and other areas, DOT programs have been successful in the control and treatment of TB. Similarly, nursing case management offers a comprehensive approach to TB treatment, assigning outreach workers, initiating DOT, and assisting the TB patient with any necessary services to ensure compliance with therapy. According to the responses to the survey conducted for this study, public health departments in all states reported the use of DOT programs and most states utilized nursing case management.

The increased use of nursing case management, TB outreach workers, and DOT programs to treat and control TB may require increased public health expenditures during the short term in a political environment of contracting public resources. However, the costs of the resurgence of TB has been projected at $20,000 per case in 1990 dollars.[56] Each hospitalization for multi-drug resistant TB can cost

$200,000, which is the equivalent to the cost of providing DOT to 700 TB patients.[57] Each dollar spent on TB control programs produces savings of three to four dollars in averted TB treatment costs, with even greater savings produced by controlling multi-drug resistant TB.[58] Hence, nursing case management, DOT, outreach workers and other TB control efforts are highly cost/effective? Evaluating TB patients for eligibility for Medicaid, Medicare, and the Ryan White programs can provide resources to care for people with TB. The home and community-based care programs funded by Medicaid and by Title II of the CARE Act can be especially helpful to public health departments in the fight against TB, covering case managers, outreach workers, and the health professionals for DOT programs provided to eligible people with TB.

The results of the survey conducted for this study indicate that public health departments in almost all states are implementing the programs and policies that TB experts advocate to control this disease. The implementation of these TB policies and programs, combined with dramatically increased federal funding for TB control during federal fiscal year 1993, may help to explain why the incidence of TB resumed its long term decline in the United States in 1993 after a decade of resurgence. The resurgence of TB in the United States during the 1980s, however, illustrates that the danger of TB to the nation's health is a constant threat. Utilizing Medicaid, Medicare, and the programs funded by the Ryan White CARE Act can provide additional resources to fund case management, directly observed therapy, outreach programs, and other services that are effective at combatting TB among people with HIV infection.

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Chapter 11
Summary and Conclusions

Objectives

The objectives of this study are to describe and analyze a range of state-administered, government programs available to cover and finance the health care needed by people who are infected with the human immunodeficiency virus (HIV). The study focuses on: Title II programs of the Ryan White CARE Act; Medicaid 2176 home and community-based care waivers; state-funded, non-Medicaid, medical assistance programs (MAP); and the actions of state health departments that address the incidence of tuberculosis (TB), especially among people with HIV illness. The research also presents assessments that administrators of AIDS service organizations (ASOs) at the state and local level have about how well each of these state-administered public programs (as well as the federal Medicare program) addresses the health care needs of people with HIV in their states.

Survey Results

The project collected data on these state-administered public programs with a series of nine separate surveys that were mailed to program administrators in each state during 1995 through 1997. These surveys of the administrators of the various state-administered public programs identify states that have developed innovative policies to assist people with HIV gain access to needed health services. These innovative policies can then be used as models to assist other states in the development of similar AIDS-related policies for their states.

Title II Programs

The Ryan White Comprehensive AIDS Resource Emergency (CARE) Act became law in August, 1990 with the objective to improve both the quality and availability of care for people with HIV disease and their families. Tile II of the CARE Act allows states to allocate funds among any or all of four areas: to cover home-based health services; to provide medication and other treatments; to continue private health insurance coverage; or to fund HIV care consortia.

Title II Funding Allocations. The study presents how the states are allocating Title II funds, with most states spending the largest share of Tile II funds on HIV consortia.[a] Among the programs and services that Title II administrators considered to be most effective at meeting the care needs of people living with HIV are: the HIV consortia; the HIV/AIDS DAPs; case management; and various home health services. The Title II administrators in most states expect the number of Title II beneficiaries to increase. If federal funding for Title II programs does not increase to keep pace with the increasing number of people expected to receive Tile II benefits, then the Title II programs may not be able to provide services for all eligible people.

Consortia. The study identified a range of medical and support services that the HIV consortia funded by Tile II provided during 1995 in the various states. Among the most effective consortia services identified by the study are: case management, primary medical care, drugs/medication, dental care, and home care. However, as the response from a Title II administrator in Florida summarized: "a single service

[a] The Title II surveys were completed before the approval by the Food and Drug Administration of the protease inhibitors. The expense of these new drugs, when used in combination therapies, may change this allocation of funding among Title II programs.

cannot be identified as [most effective]. It is the continuum of care that makes Title II effective - the broad array of services covered [in Florida]." The services identified in Table 2-3 in the Final Report of this study offer examples of the broad array of medical and support services that comprise the continuum of care needed by people with HIV illness to guide the HIV consortia funded by Title II.

The study also identified the medical and financial criteria necessary for individuals to become eligible for HIV consortia services. The study documents that the state Title II programs have established generous income eligibility standards for services provided by HIV consortia, especially when compared to Medicaid eligibility standards. Hence, HIV consortia funded by Tile II can provide services to people infected with HIV who have incomes too high to become eligible for Medicaid coverage.

To coordinate HIV consortia programs with the state Medicaid programs, Medicaid representatives serve on Title II boards and committees in a number of states. In addition, case managers can assist individuals who have HIV disease with the Medicaid eligibility process. This role for case managers is important because a number of state AIDS program directors identified the Medicaid eligibility/application process as a barrier to the coordination of Medicaid with the Title II programs. Another barrier to Medicaid/Title II integration and coordination mentioned by AIDS program directors in a number of states is the administrative separation of the two programs in different state agencies. Coordinated meetings and cross-training programs can help overcome the integration problems created by this separate administration of the Medicaid and Title II programs.

Generous eligibility criteria and coverage of a broad array of medical and support services by HIV consortia allow these Title II programs to strengthen the public-sector safety net for financing the care needed by people with HIV-related illness. HIV consortia funded by Tile II provide needed care to people with HIV disease before they become eligible for Medicaid or Medicare.[b]

HIV/AIDS Drug Assistance Programs. Most Tile It-funded DAPs had formularies, with the number of drugs included ranging as high as 191 medications in New York during 1995. The decision to add new drugs to the DAP formulary is made by a board, panel, or committee in most states, with a number of states noting that the cost of medications or the availability of funds affects these decisions. Although it would allow health providers to prescribe the most appropriate drug therapies, the DAPs in some states do not allow the off-label use of medications.

The study also identified the medical and financial criteria necessary for individuals to become eligible for DAPs. The study documents that the state Title II programs have established generous income eligibility standards for services provided by DAPs, especially when compared to Medicaid eligibility standards. Hence, DAPs funded by Title II can provide drug therapies to people infected with HIV who have incomes too high to become eligible for Medicaid coverage.

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[b] For a person with HIV illness to become eligible for Medicare requires meeting eligibility criteria for Social Security Disability Insurance (SSDI), including disability status, sufficient work-related history, and a 29-month waiting period (5 months from disability status for SSDI payment to begin, then 24 additional months for Medicare coverage to begin). (See Baily, M., Bilheimer, L., Woolridge, J., Langwell, K., and Greenberg, W. "Economic Consequences for Medicaid of Human lmmunodeficiency Virus Infection." Health Care Financing Review (1990 Annual Supplement): 97-108.

DAPs funded by Title II in a number of states cover the prescription drug needs of Medicaid recipients with HIV or AIDS in excess of the Medicaid limits implemented in these states. However, the DAP in South Carolina responded that due to the lack of funds it can no longer cover the drugs needed by Medicaid recipients with HIV or AIDS that exceed the drug utilization limits implemented by the Medicaid programs in that state. DAPs also can provide drug coverage to people with AIDS or HIV who are in the process of becoming eligible for Medicaid benefits.

DAPs in a number of states reported the use of waiting lists. Given the encouraging results of the new protease inhibitors in treating HIV infection, and the $12,000 to $15,000 annual cost of these and other drugs per person when used in a combination therapy or a "three-drug cocktail", the DAPs funded by Title II will face increasing fiscal pressures (Altman, 1996; Winslow, 1996). In fact, some states are already tightening eligibility, reducing the number of covered drugs, or implementing copayments (McGinley, 1996). If federal funding for Tile II programs in the future does not keep pace with the expected increase in the number of people eligible for Title II services, and the costs of services provided, then the public-sector safety net for financing HIV-related care will be weakened.

Home and Community-Based Care. The study identified a range of home and community-based care services funded by Title II in various states during 1995. Among the most effective services identified by the study are: case management, personal/attendant care, homemaker/chore services, home I.V. therapy, and transportation.

Coordination of the Title II programs with the Medicaid Home and Community-Based Care Waiver programs will increase the range of services available to people

with AIDS and HIV infection while conserving limited Title II resources. Contracting with Medicaid-certified providers of home and community-based services will allow the Title II programs to promote the continuity of care as patients become eligible for Medicaid, as well as help assure that Title II is the payer of last resort.

Health Insurance Continuation Programs. In all states implementing the health insurance continuation program with Title II funds, the programs cover health insurance premiums, with a few states also covering copayments, coinsurance, and/or deductibles. The study documents that the state Tile II programs have established generous income eligibility standards for assistance provided by the health insurance continuation programs. Hence, the health insurance continuation programs funded by Tile II can provide coverage to people infected with HIV who have incomes too high to become eligible for Medicaid coverage.

Title II Summary. Generous eligibility criteria and coverage of a broad array of health services by the programs funded by Title II of the CARE Act strengthens the public-sector safety net for financing the care needed by people with HIV-related illness. Tile II programs provide needed care to people with HIV disease before they become eligible for Medicaid or Medicare. Generous eligibility criteria (or no income restrictions in some states), however, can become a double-edged sword. If federal funding for Title II programs is not sufficiently increased to keep up with the increasing number of people expected to receive benefits from Tile II programs, or if future federal Medicaid reform allows the states to establish even more restrictive Medicaid eligibility standards, then the Tile II programs may not be able to provide services for all eligible people. This could result in the use of waiting lists, reduced services, some other forms of rationing, or the implementation of more restrictive eligibility criteria. For

example, the DAPs funded by Title II of the CARE Act in a number of states have implemented waiting lists for people to receive medications because funding is not adequate to meet the need for this coverage. If federal funding for Title II programs in the future does not keep pace with the expected increase in the number of people eligible for Title II services, then the public-sector safety net for financing HIV-related care will be weakened.

Medicaid Home and Community-Based Care Waivers

The Medicaid Home and Community-Based Care Waiver programs allow the states considerable flexibility in defining the groups of people to be served and the range of services to provide. These waivers allow the states to implement innovative programs to provide community-based, long-term care to people with AIDS. Given their disability status, people with AIDS who meet the more generous eligibility standards established for these waiver programs may receive services from the Medicaid Home and Community-Based Care waiver programs for the Elderly and Disabled or from a-separate waiver for the Disabled (Buchanan, 1996).[c] In addition, 15 states and the District of Columbia (implemented in December, 1996) have established AIDS-specific Medicaid Home and Community-Based Care waiver programs and Maine expects to implement this AIDS-specific waiver during 1997.

Case management services are advocated as critical to the care of people with AIDS, with the role of the case manager extending beyond the coordination of health services to include helping people with AIDS cope with their social and emotional needs. As Tables 6-1, 6-3, and 6-5 in the Final Report for this project demonstrate,

[c] These waiver programs for the disabled, however, are limited in many states to the developmentally disabled.

the Medicaid Home and Community-Based Care waiver programs for people with AIDS, the Elderly and Disabled, and for the Disabled offer case management services in most states. Case management was identified by Medicaid administrators in the survey conducted for this research as among the most effective waiver services provided to people with AIDS. Other services provided by these waiver programs that the Medicaid administrators identified as most effective at meeting the care needs of people with AIDS are: personal care, homemaker services, assistive technologies, emergency response, medical social services, in-home and inpatient respite care, counseling, home intravenous therapy, nutritional counseling and supplements, attendant care, hospice care, home-delivered meals, and unlimited prescription drug coverage. (See Tables 6-2, 6-4, and 6-6 in the Final Report.) State Medicaid programs not administering the AIDS-specific waiver program can include these services in their waiver programs for the elderly and disabled. Since people with AIDS are typically eligible for these waiver programs due to their disability status, even states without the AIDS-specific waiver can then offer Medicaid recipients with AIDS a broad range of needed home care and community-based services.

State-Funded Medical Assistance Programs

A number of states implement state-funded MAPs to provide health care to low-income people. However, a review of the literature revealed no published papers that describe these programs. A two-step survey process was used to identify states that implemented state-funded MAPs during 1997 and to collect data describing eligibility, coverage, and payment policies for these programs.

Typically, requirements for MAP eligibility are restrictive but the range of health services covered tends to be comprehensive in most states. MAP payment levels for

the health services included in the study typically are less than the Medicaid payment level, which may make it diicult for MAP beneficiaries to gain access to these services. In spite of these eligibility and payment level restrictions, these state-funded MAPs can provide health coverage to people with HIV disease who lack other health insurance. As Table 7-2 in the Final Report illustrates, most of these state-funded MAPs cover a comprehensive range of health services needed by people infected with HIV, including acute care services and prescription drugs, as well as necessary home and community-based care and support services.

AIDS Service Organizations

Public programs are the primary payers for the health and care-related services provided to people with HIV. The coverage, payment, and utilization policies implemented by these public programs affect the care that people with HIV receive. ASOs were surveyed to identify effective services covered, and effective services that are not covered, by these public payers of HIV-related care, as well as to identify problems that people with HIV illness have with these programs.

As Table 8-1 in the Final Report illustrates, the state Medicaid programs cover a range of health services that meet the needs of people with HIV, with prescription drug coverage mentioned most frequently by the ASOs. However, a number of states place restrictive utilization limits on these health services (for example, three prescriptions per month), often below the levels needed by people with HIV illness. Table 8-1 in the Final Report also presents effective health and care-related services that the state Medicaid programs do not cover. All of these services can be provided with the Medicaid home and community-based care waiver programs for people with AIDS/HIV and for the elderly and disabled (people with AIDS can access this programs due to

their disability status). Expanded use of these waiver programs would allow the state Medicaid programs to target effective health and care-related services to people with HIV illness. In addition, due to more generous income eligibility standards, it is easier for people with HIV to qualify for these waiver services than for traditional Medicaid coverage (Buchanan, 1996).

Table 8-2 in the Final Report presents effective health and care-related services provided to people with HIV that are funded by Tile II of the Ryan White CARE Act. In addition to prescription drugs and physician services, the Title II programs offer support-related services such as food and nutrition, transportation, alternative therapies, mental health and support groups, adult and child day care, and legal services. Limited funding for Title II programs was the problem most frequently identified by the ASOs. A number of ASOs also mentioned a lack of awareness of Title II programs as a problem for people with HIV illness.

As Table 8-3 in the Final Report summarizes, the ASOs identified a blend of both health care and social services funded by Title I of the Ryan White CARE Act as most effective at meeting the needs of people with HIV illness. One AS0 responded that the Title I program in its service area does not cover support services for family and friends of people with HIV disease, with these people feeling "left out." Another AS0 reported the lack of transportation to care results in the loss of care.

As Table 8-4 in the Final Report presents, the Medicare program covers a range of health services necessary for the treatment of acute illness, except for prescription drugs. Given the success of the combination drug therapies in combatting the progression of HIV disease, the ASOs identified the lack of Medicare coverage of prescription drugs as a major problem for people with HIV illness. One AS0

responded that if Medicare was "the only health insurance a disabled person has, lack of access to medications is a significant problem." Another AS0 noted that given the focus of Medicare coverage on acute care/medical care, the lack of Medicare coverage of support services is a problem for people with HIV disease. The length of time for Medicare eligibility (29 months) is a severe problem for people with HIV illness. Medicare cost sharing responsibilities can be more than most people with AIDS can afford.

One AS0 responded that the Title II programs need to address the concerns of people who may recover from HIV-related disability with job and re-education programs. Given the success of the combination drug therapies in combatting the progression of HIV disease, all public programs covering HIV-related care, not just the CARE Act programs, will need to address the health and care-related needs of people who recover from HIV-related disability. If people recover from HIV-related disability, will they lose their disability status? This disability status, for example, is a key element of eligibility for Medicaid coverage. Without this coverage, will they still have access to the combination drug therapies and other health and care-related services that led to their recovery? The eligibility of people who recover from HIV-related disability for public programs will become an increasingly important issue in the near future as new developments in drug therapies and other treatments combat the progression of HIV disease.

Tuberculosis Control Policies

Incentives and Enablers for Compliance with TB Drug Regimens. The results of the survey conducted for this study indicate that public health departments in almost all states are implementing the incentives and enablers that TB experts

advocate to encourage patients to comply with drug regimens in efforts to control this disease. The implementation of these TB incentives, along with public health screening and treatment programs combined with dramatically increased federal funding for TB control during federal fiscal year 1993, may help to explain why the incidence of TB resumed its long term decline in the United States in 1993 after a decade of resurgence.

Public Programs to Fund Treatment Services. Aggravating and enhancing the threat of TB in the United States has been the emergence of AIDS. The spread of TB among people with AIDS has important public health consequences because TB may be the only AIDS-related disease that can be transmitted to people who are not infected with HIV (Hopewell, 1992). With the increasing incidence of AIDS in the United States, public health programs must be maintained and expanded to control TB to protect the public health and the health of people with AIDS.

Based on the results observed in New York City and other areas, DOT programs have been successful in the control and treatment of TB. Similarly, nursing case management offers a comprehensive approach to TB treatment, assigning outreach workers, initiating DOT, and assisting the TB patient with any necessary services to ensure compliance with therapy. According to the responses to the survey conducted for this study, public health departments in all states reported the use of DOT programs and most states utilized nursing case management.

The increased use of nursing case management, TB outreach workers, and DOT programs to treat and control TB may require increased public health expenditures during the short term in a political environment of contracting public resources. However, each dollar spent on TB control programs produces savings of

three to four dollars in averted TB treatment costs, with even greater savings produced by controlling multi-drug resistant TB Institute of Medicine, 1992). Hence, nursing case management, DOT, outreach workers and other TB control efforts are highly cost/effective (Frieden, et al., 1995).

Evaluating TB patients for eligibility for Medicaid, Medicare, and the Ryan White programs can provide resources to care for people with TB. The home and community-based care programs funded by Medicaid and by Title II of the CARE Act can be especially helpful to public health departments in the fight against TB, covering case managers, outreach workers, and the health professionals for DOT programs provided to eligible people with TB.

The results of the survey conducted for this study indicate that public health departments in almost all states are implementing the programs and policies that TB experts advocate to control this disease. The resurgence of TB in the United States during the 1980s, however, illustrates that the danger of TB to the nation's health is a constant threat. Utilizing Medicaid, Medicare, and the programs funded by the Ryan White CARE Act can provide additional resources to fund case management, directly observed therapy, outreach programs, and other services that are effective at combatting TB among people with HIV infection.

Policy Implications

This study creates a state-by-state archive of state-administered health programs available to people with HIV. These data help identify any holes in the public-sector safety net of health coverage for people with HIV-related conditions and identify other state-administered programs that help close these gaps in coverage. Successful innovations developed by individual states that develop a comprehensive

range of state-administered programs can serve as models to guide other states in developing AIDS-related policies that assure all people with HIV have access to necessary social and health services.

Conclusions

Given the success of the combination drug therapies in combatting the progression of HIV disease, all public programs covering HIV-related care will need to address the health and care-related needs of people who recover from HIV-related disability. If people recover from HIV-related disability, will they lose their disability status? This disability status, for example, is a key element of eligibility for Medicaid coverage. Without this coverage, will they still have access to the combination drug therapies and other health and care-related services that led to their recovery? The eligibility of people who recover from HIV-related disability for public programs will become an increasingly important issue in the near future as new developments in drug therapies and other treatments combat the progression of HIV disease. The recovery from HIV-related disability and adequate funding for public programs to provide health coverage to people with HIV are among the most important HIV-related issues in future public policy debates.

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Appendix 1:
List of Publications Resulting From the Study

Published:

R.J. Buchanan. "Tuberculosis and HIV Infection: Utilization of Public Programs to Fund Treatment Services," AIDS AND PUBLIC POLICY JOURNAL, Vol. 12, No. 4, 1997, forthcoming.

R.J. Buchanan and B. Chakravorty. 'The Medicaid Home and Community-Based Care Waiver Programs: Providing Services to People with AIDS," HEALTH CARE FINANCING REVIEW, Vol. 18, No. 4, 1997.

R.J. Buchanan. 'The Ryan White CARE Act: The States' Allocation of Title II Funding Among Programs," AIDS AND PUBLIC POLICY JOURNAL, Vol 12, No. 3, 1997.

R.J. Buchanan. "Compliance with TB Drug Regimens: Incentives and Enablers Offered by Public Health Departments," AMERICAN JOURNAL OF PUBLIC HEALTH, Vol. 87, No. 12, 1997.

R.J. Buchanan. "Health Insurance Continuation Programs Funded by Tile II of the Ryan White CARE Act: A Survey of the States," AIDS AND PUBLIC POLICY JOURNAL, Vol. 12, No. 2, 1997.

R.J. Buchanan. "Home and Community-Based Care Funded by Title II of the Ryan White CARE Act: A Survey of the States," AIDS AND PUBLIC POLICY JOURNAL, Vol. 12, No. 1, 1997.

R.J. Buchanan and S.R. Smith. "Drug Assistance Programs Funded by Title II of the Ryan White CARE Act: A Survey of the States," AIDS AND PUBLIC POLICY JOURNAL, Vol. 11, No. 4, 1996.

R.J. Buchanan. "Consortia Services Funded by Title II of the Ryan White CARE Act: A Survey of the States," AIDS AND PUBLIC POLICY JOURNAL, Vol. 11, No. 3, 1996.

Under Publication Review:

R.J. Buchanan. "State-Funded Medical Assistance Programs: Sources of Health Coverage for People with HIV Illness."

R.J. Buchanan and B. Chakravorty. "Assessments of the Coverage of HIV-Related Care by Public Programs: A Survey of AIDS Service Organizations."

Please do not quote or distribute data from the two articles under publication review. Please contact the principal investigator for publication developments, or for citation suggestions, concerning the chapters under publication review.

Appendii 2
Table 6-7
Expendiiures for Services Provided to Waiver Recipients at the Acute Level with the AIDS-Specific, Home 8 Community-Based Care Waivers (Annual Report on Home and Community-Based Services Waivers)

	Average Per Capita Expenditures for Institutional Services Provided to Acute-Level Recipients:		Average Per Capita Expenditures for Acute Care Services Provided to Acute-Level Institutional Services Recipients:	
	Non-waiver Recipients	Waiver Recipients	Non-waiver Recipients	Waiver Recipients
California (initial report)	$10,386 (1/1/92 - 12/31/92)	$8,768	$884 (1/1/92 - 12/31/92)	$1,654
Colorado (initial report)	$10,430 (1/1/95 - 12/31/95)	$8,606	$951 (1/1/95 - 12/31/95)	$1,261
Delaware	not available	not available	not available	not available
Florida (lag report)	$16,568 (1/1/92 - 12/31/92)	$13,723	$5,601 (1/1/92 - 12/31/92)	$1,841
Hawaii (lag report)	$30,699 (6/01/92 - 05/31/93)	$20,755	$10,222 (6/01/92 - 05/31/93)	$8,860
Illinois (lag report)	$32,391 (10/01/92 - 09/30/93)	$37,475	$4,725 (10/01/92 - 09/30/93)	$3,756
Iowa (initial report)	$1,419 (07/01/93 - 06/30/94)	not applicable	$1,343 (07/01/93 - 06/30/94)	not applicable
Maine	Maine expects to implement an AIDS-specific waiver during 1997			
Marytand	Maryland does not have an AIDS-specific, Medicaid Home and Community-Based Waiver, but implements the program "HIV Targeted Case Management Services". (See Table 5) This program served 780 people during 1994.			
Missouri (lag report)	$9,122/98 7/01/93-6/30/94	$14,157.55 7/01/93-6/30/94	$8.157.75 7/01/93-6/30/94	$4,472.58 7/01/93-6/30/94
New Jersey	HCFA 372 Lag Report not available at the time of the survey due to a change in fiscal agents			
New Mexico (initial report)	$11,777 (07/01/91 - 06/30/92)	$7,907	81,888 (07/01/91 - 06/30/92)	$1,469
North Carolina	North Carolina will implement an AIDS-specific, Medicaid Home and Community-Based Waiver effective 1 1/1/95			
Pennsylvania (initial report)	not available (04/01/93 - 03/31/94)	not available	not available (04/01/93 - 03/31/94)	not available
South Carolina (initial report)	not applicable (10/01/93 - 09/30/94)	not applicable	not applicable (10/01/93 - 09/30/94)	not appticabie
Virginia	not available	not available	not available	not available
Washington (lag report)	$15,871 (07/01/92 - 06/30/93)	$12,349	$8,748 (07/01/92 - 06/30/93)	$11,241

Source: Robert J. Buchanan, Ph.D., Department of Community Health, University of Illinois, a 1995 survey of the state Medicaid programs. Thii research was funded by a grant from the Heaith Care Financing Administration, U.S. Department of Health and Human Services (grant # 18-P-90286/5-01).

Appendix 2
Table 6-8
Expenditures for Services Provided to Waiver Recipients at the Nursing Facility Level
with the AIDS-Specific, Home 8 Community-Based Care Waiver6
(Annual Report on Home and Community-Based Services Waivers)

	Average Per Capita Expenditures for Institutional Services Provided to NF-Level Recipients:		Average Per Capita Expenditures for Acute Care Services Provided to NF-Level Institutional Services Recipients:	
	Non-waiver Recipients	Waiver Recipients	Non-waiver Recipients	Waiver Recipients
California (initial report)	$4,599 (SNF level)	$6,189 (SNF level)	$1,117 (SNF level)	$1,670 (SNF level)
	(1/1/92 - 12/31/92)		(1/1/92 - 12/31/92)	
Colorado (initial report)	$16,193 (NF level)	$8,286 (NF level)	$4,962 (NF level)	$3,263 (NF level)
	(1/1/95 - 12/31/95)		(1/1/95 - 12/31/95)	
Delaware	not available	not available	not available	not available
Florida (lag report)	$15,493 (NF level)	$11,878 (NF level)	$5,080 (NF level)	$1,096 (NF level)
	(1/1/92 - 12/31/92)		(1/1/92 - 12/31/92)	
Hawaii (lag report)	not applicable	not applicable	not applicable	not applicable
	(6/01/92 - 05/31/93)		(6/01/92 - 05/31/93)	
Illinois (lag report)	not applicable (NF level)	not applicable (NF level)	not applicable (NF level)	not applicable (NF level)
	(10/01/92 - 09/30/93)		(10/01/92 - 09/30/93)	
Iowa initial report)	not applicable (SNF level)	not applicable (SNF level)	$1,525 (SNF level)	$17 (SNF level)
	(07/01/93 - 06/30/94)		(07/01/93 - 06/30/94)	
Maine	Maine expects to implement an AIDS-specific waiver during 1997			
Maryland	Maryland does not have an AIDS-specific, Medicaid Home and Community-Based Waiver, but implements the program "HIV Targeted Case Management Services". (See Table 5) This program served 760 people during 1994.			
Missouri (lag report)	not applicable (NF level) 7/01/93-6/30/94	not applicable (NF level) 7/01/93-6/30/94	not applicable (NF level) 7/01/93-6/30/94	not applicable (NF level) 7/01/93-6/30/94
New Jersey	HCFA 372 Lag Report not available at the time of the survey due to a change in fiscal agents			
New Mexico (initial report)	not applicable (NF level)	not applicable (NF level)	not applicable (NF level)	not applicable (NF level)
	(07/01/91 - 06/30/92)		(07/01/91 - 06/30/92)	
North Carolina	North Carolina will implement an AIDS-specific, Medicaid Home and Community-Based Waiver effective 11/1/95			
Pennsylvania (initial report)	not available	not available	not available	not available
	(04/01/93 - 03/31/94)		(04/01/93 - 03/31/94)	
South Carolina (initial report)	$9,456 (NF level)	not applicable (NF level)	$2,391 (NF level)	not applicable (NF level)
	(10/01/93 - 09/30/94)		(10/01/93 - 09/30/94)	
Virginia	not available	not available	not available	not available
Washington (lag report)	not applicable (NF level)	not applicable (NF level)	not applicable (NF level)	not applicable (NF level)
	(07/01/92 - 06/30/93)		(07/01/92 - 06/30/93)	

Source: Robert J. Buchanan, Ph.D., Department of Community Health, University of Illinois, a 1995 survey of the state Medicaid programs. This research was funded by a grant from the Health Care Financing Administration, U.S. Department of Health and Human Services (grant # 18-P-90286/5-01).